DOCUMENT RESUME

ED 200 794 CE 028 600

AUTHOR Perlman, Leonard G., Ed.
TITLE The Role of Vocational Rehabilitation in the 1980's: Serving Those with Invisible Handicaps Such as Cancer, Cardiac Illness, Epilepsy. A Report of the Mary E. Switzer Memorial Seminar (3rd, Denver, Colorado, June 5-7, 1978).
INSTITUTION National Rehabilitation Association, Alexandria, Va.
SPONS AGENCY National Cancer Inst. (NIH), Bethesda, Md.
PUB DATE 79
NOTE 98p.; For a related document se CE 028 601.

EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS Attitude Change; *Cancer; Change Strategies; Community Involvement; Delivery Systems; Disabilities; *Epilepsy; Equal Opportunities (Jobs); Family Involvement; Family Relationship; *Heart Disorders; Legislation; Needs; *Needs Assessment; Participation; Policy Formation; Program Development; Research Needs; Services; *Social Bias; Social Discrimination; Socialization; Special Health Problems; Staff Development; Vocational Education; *Vocational Rehabilitation

ABSTRACT

This publication includes six action papers presented at the Denver, Colorado, seminar on June 5-7, 1978. Three disability categories highlighted in the seminar are the topics of the papers: cancer, cardiac illness, and epilepsy. There are two papers devoted to each category of disability, one focusing on action for eliminating barriers to employment and community participation and another focusing on action for improving socialization and family support and methods for reducing stigma and negative attitudes. Each paper, presented as a separate chapter, is headed by an excerpt or two from critiques of the Action Papers by the eighteen Fellows who wrote the papers. Following each pair of chapters is a list of implications for action in the training of personnel, program and policy development, service delivery, research, and legislative initiatives, as distilled from the consensus of the Fellows. The final chapter deals with the commonalities of the "invisible handicaps." (YLB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED200794

THE ROLE OF VOCATIONAL REHABILITATION IN THE 1980's SERVING THOSE WITH INVISIBLE HANDICAPS SUCH AS CANCER, CARDIAC ILLNESS, EPILEPSY

A REPORT OF THE THIRD MARY E. SWITZER MEMORIAL SEMINAR

DECEMBER 1978

EDITOR: LEONARD G. PERLMAN, D.Ed.

PUBLISHED BY

NATIONAL REHABILITATION ASSOCIATION
1522 K Street, N.W.
Washington, D.C. 20005

CE 028 600

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Leonard G. Perlman

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

This monograph was funded in part by the National Cancer Institute, National Institutes of Health, Department of Health, Education, and Welfare (PD #289472).

Copyright -- National Rehabilitation Association, 1979

TABLE OF CONTENTS

		Page
FOREWORD		ii
PREFACE		iii
ACKNOWLEDGMENTS		iv
SEMINAR PARTICIPANTS		v
PLANNING COMMITTEE MEMBERS		vi
INTRODUCTION		vii
CHAPTER 1.	Cancer: Action for Reducing Barriers to Employment and Community Participation	1
CHAPTER 2.	Cancer: Action for Improving Socialization and Family Support, and Reducing Stigma and Negative Attitudes	15
CHAPTER 3.	Epilepsy: Action for Reducing Barriers to Employment and Community Participation	36
CHAPTER 4.	Epilepsy: Action for Improving Socialization and Family Support, and Reducing Stigma and Negative Attitudes	46
CHAPTER 5.	Cardiac Illness: Action for Reducing Barriers to Employment and Community Participation	62
CHAPTER 6.	Cardiac Illness: Action for Improving Socialization and Family Support, and Reducing Stigma and Negative Attitudes	70
CHAPTER 7.	Commonalities of the Invisible Handicaps	80
National Rehabilitation Association Board of Directors		86

FOREWORD

The National Rehabilitation Association, honoring Mary E. Switzer by presenting memorial seminars each year in her memory, strives to keep as its living trust, the tenets and meaning of her life and its purposes through meaningful participation in them by the general rehabilitation community.

In presenting this publication on invisible disabilities, resulting from such generous participation, the National Rehabilitation Association-sponsored Mary E. Switzer seminar has studied persons often excluded from services, treatment and the dramatic attention we accord those persons with visible disabilities. The lack of general information, the lack of awareness of commonality through the disabling conditions, the lack of public support and the lack of participation of advocates for persons so disabled are some of the problems inherent in this monograph.

The Mary E. Switzer seminar on invisible disabilities, as a catalyst for awareness for community participation, for family support, can also sensitize employers to the many persons in their establishment who need recognition of their special status, assistance in providing access to work adjustment counseling, access to positive information and access to other services related to hidden disabilities.

With the distribution of this report, the National Rehabilitation Association, while aware of the fact that we do not have all the answers to such a complex area of concern, trust that interested parties will be encouraged to explore hidden disabilities at other levels for programs, progress and accessibility in the tradition of Mary E. Switzer.

Elizabeth H. Anderson
President
National Rehabilitation Association

PREFACE

It was indeed a pleasure to have the opportunity to serve on the Planning Committee and as a Fellow for the Third Annual Mary E. Switzer Memorial Seminar. The significance of this seminar and its by-product, a monograph of recommendations for actions in rehabilitation, is extremely important to those concerned with the many hidden disabilities, but it is even more timely and significant to those working in the field of cancer rehabilitation.

There has been a tremendous gap in the vocational rehabilitation services available for the cancer patient and the transfer of technology in the total rehabilitation of this population of patients has not kept pace with some of the more visible and less feared handicaps. For too long, many persons diagnosed and treated for cancer have not received the rehabilitation services morally and legally due them. The lack of providing needed rehabilitation services for cancer patients has been largely due to lack of information and archaic stereotypes as to the potential of the cancer patient to successfully utilize rehabilitation.

This report then should serve to stimulate the much needed thought and more needed action on behalf of those with cancer and other hidden disabilities. Many of these persons are able to return to work and to function as active, productive citizens once proper rehabilitation services are made available to them.

Lawrence D. Burke
Program Director for Rehabilitation
Division of Cancer Control and Rehabilitation
National Cancer Institute

ACKNOWLEDGEMENTS

The Third Mary E. Switzer Memorial Seminar, which served as a basis for this report, was made possible by an appropriation from the Mary E. Switzer Memorial Fund and the Division of Cancer Control and Rehabilitation of the National Cancer Institute. It should be noted that funds were initially raised in a national campaign, headed by Olive Banister, to establish a memorial to Mary E. Switzer to whom tribute is paid in this monograph. The Board of Directors of the National Rehabilitation Association (NRA) agreed to use approximately one-half of the fund to support seminars on topics vital to the rehabilitation of handicapped persons. The other half of the fund is used to support fellowships to rehabilitation practitioners to explore issues of concern to the Rehabilitation movement.

Thanks are expressed to the Seminar Planning Committee for their excellent direction and guidance in the development of the Seminar; to Richard P. Oestreich, Executive Director, NRA, and his staff whose assistance was always available; to Henry Williams, Chairperson, Commission on Professional Concerns, for his constant encouragement and support; and to Gerry Perlman for editorial assistance, James E. Gorman for final proofing and Zelma Baughman for typing the manuscript.

Gratitude is, of course, expressed to the "Switzer Fellows" whose thoughts and recommendations are presented in this report; to Dr. James F. Garrett, Vice President, World Rehabilitation Fund for his excellence in Chairing the Seminar; to Ms. Judy Spolum, CRC, who so ably coordinated the numerous details at the Seminar in Denver, Colorado; and to our gracious co-hosts, the University of Colorado Medical Center and the Colorado Regional Cancer Center, Inc.

Special appreciation is due Olive Banister and Dr. Betty Hedgeman, Chairpersons of the Switzer Memorial Committee, for their guidance and encouragement throughout this project and the many donors to the Mary E. Switzer Memorial Fund which helps to perpetuate the memory of a great leader in the field of Rehabilitation.

Leonard G. Perlman, Ed.D.
Coordinator, Mary E. Switzer Memorial Seminars

PARTICIPANTS IN THE MARY E. SWITZER MEMORIAL SEMINAR
DENVER, COLORADO

Olive K. Banister
Project Director
The Cancer Center, Inc.
Cleveland, Ohio

Mr. Abraham Brickner, ACSW
Director, Community Programs
Michigan Cancer Foundation
Detroit, Michigan

Sterling B. Brinkley, M.D.
Director Medical Affairs
Rehabilitation Services Administration
Washington, D. C.

Mr. Lawrence D. Burke, MSW
Program Director for Rehabilitation
National Cancer Institute
Bethesda, Maryland

G. Fred Cromes, Jr., Ph.D.
Professor and Chairman
Div. of Voc. Rehabilitation
University of Texas
Dallas, Texas

William Gellman, Ph.D.
Rehabilitation Training Program
DePaul University
Chicago, Illinois

John Goldschmidt, M.D.
Rehabilitation Institute of Chicago
Northwestern University
Chicago, Illinois

Mr. Hank Graden, CRC
Specialist for Physical Disabilities
Div. of Vocational Rehabilitation
Raleigh, North Carolina

Morris C. Hansen, CRC
Staff Development Specialist
Division of Rehabilitation Services
Salt Lake City, Utah

James F. Garrett, Ph.D, Chairperson
World Rehabilitation Fund
Washington, D.C.

Lawrence C. Hartlage, Ph.D.
Professor
Department of Neurology
Medical College of Georgia
Augusta, Georgia

Betty Hedgeman, Ph.D.
Executive Director
Epilepsy Foundation of Greater N.Y. City
New York, New York

Melvin J. Krant, M.D.
Director of Cancer Program
University of Massachusetts
Worcester, Massachusetts

Robert M. Levenson, M.D.
Internal Medicine & Cardiology
Seattle, Washington

Matthew Maxon, M.A.
Assistant Director
Div. of Education & Community Programs
American Heart Association
Dallas, Texas

David I. Mostofsky, Ph.D.
Professor of Psychology
Boston University
Boston, Massachusetts

Joyce Pigg, CRC
Department of Rehabilitation
Redwood City, California

Ms. Judy Spolum, CRC
Program Director of Rehabilitation
Colorado Regional Cancer Center, Inc.
Denver, Colorado

Mr. Jerry L. Starkweather
Associate Superintendent & Director
Division of Vocational Rehabilitation
Des Moines, Iowa

Leonard G. Perlman, Ed.D., Coordinator
Switzer Memorial Seminars
Washington, D.C.

PLANNING COMMITTEE MEMBERS FOR THE THIRD MARY E. SWITZER MEMORIAL SEMINAR

Olive K. Banister, Chairperson, Mary E. Switzer Memorial Committee

Abraham Brickner, ACSW, Michigan Cancer Foundation

Sterling B. Brinkley, M.D., Rehabilitation Services Administration, DHEW

Lawrence Burke, M.S.W., National Cancer Institute, National Institutes of Health

James F. Garrett, Ph.D., World Rehabilitation Fund

Betty Hedgeman, Ph.D., Chairperson, Mary E. Switzer Memorial Committee

Willman Massie, Rehabilitation Services Administration, DHEW

David Mostofsky, Ph.D., Boston University

Richard Oestreich, Executive Director, National Rehabilitation Association

Leonard G. Perlman, Ed.D., Coordinator, Mary E. Switzer Memorial Seminars

Amos Sales, Ed.D., Rehabilitation Center, University of Arizona

E. B. Whitten, Consultant & Former Director of NRA

INTRODUCTION

"I have always believed, during my many years in rehabilitation, that hope is the priceless ingredient if we are to achieve success in any type of rehabilitation for individuals. The individual's own hope is vitally important, and the hopeful outlook of therapists, physicians and counselors is equally so. It is hope that keeps the spark of life alive and moves people forward to achieve their optimum progress."

Mary E. Switzer, 1968

A decade ago, the late Miss Switzer made these remarks at an NRA Convention. It was this kind of philosophy that the Mary E. Switzer Memorial Committee set its sights for this year's Seminar topic. The same general theme was enthusiastically implemented as the Mary E. Switzer Fellows carried out their charge in Denver, Colorado in coming to grips with the various ideas and alternatives designed to provide new hope to those with the invisible handicaps.

The Third Annual Mary E. Switzer Memorial Seminar was held in Denver, Colorado from June 5 through 7, 1978, co-hosted by the University of Colorado Medical Center and the Colorado Regional Cancer Center.

The topic was the "Role of Vocational Rehabilitation in the 1980's in Serving Persons with the 'Invisible Handicaps' such as Cancer, Cardiac Illness and Epilepsy." While the three disability categories were highlighted in the Seminar, a reading of the chapters and implications obviously have some applicability to the many disabilities that may be invisible to others.

Eighteen persons, selected for their achievement, leadership and involvement with the so-called "hidden handicaps," were designated as "SWITZER FELLOWS" and received certificates to this effect.

Six "Action Papers" specifically written by the Fellows for the Seminar focused on Action for Eliminating Barriers to Employment and Community Participation, Action for Improving Socialization and Family Support; and Methods for Reducing Stigma and Negative Attitudes.

James Ballantyne, Director, Office of Rehabilitation Services, DHEW, Region VIII (Denver), welcomed the Switzer Fellows and James F. Garrett, Ph.D., Vice-President, World Rehabilitation Fund served as Chairperson.

The three-day program of intensive discussion culminated in a number of implications for action in the areas of training of personnel, program and policy development, service delivery, research and legislative initiatives. The format of this report closely follows that of the Seminar itself. Each "Action Paper," which served as a stimulus for discussion, is shown as a separate chapter. Heading each chapter is an excerpt or two from critiques of the Action Papers by the Fellows. At the end of each chapter, there is a list of the "Implications for Action." These Implications represent a distillation of the

consensus of the Fellows. The final chapter deals with the commonalities of the "Invisible Handicaps."

As we move into the next decade, it is the wish of all of us involved in this Third Mary E. Switzer Memorial Seminar that this report will not become just another catalogue number in a library, but rather a stimulus for awareness that those with invisible handicaps continue to have unmet needs. For those who read this report our question is: How can we best apply our current resources and technology to improve the rehabilitation potential of those persons with an invisible handicap?

CHAPTER 1

CANCER: ACTION FOR REDUCING BARRIERS TO EMPLOYMENT AND COMMUNITY PARTICIPATION

Author: Abraham Brickner, ACSW

"Factors influencing the vocational rehabilitation process can be described as intrinsic or extrinsic to the person with cancer. Mr. Brickner's paper focuses upon factors extrinsic to the patient, factors which he discusses as 'attitudes, beliefs, and committments (of) health care providers and vocational counselors.' His thesis is that a mechanism must be developed to impact these factors if there is to be a systematic and effective breakdown of current barriers to fulfilling the goals of the cancer control component of the National Cancer Act of 1971 and, I would add, the Rehabilitation Act of 1973.

Another point, perhaps a minor one, deserves comment. It is important to define vocational rehabilitation. Such a definition should include provision for concluding that success has occurred for a given person with cancer in the absence of working for remuneration Certainly, caring for children, one's household, one's lawn, etc. are vocational tasks."

Excerpts from comments by G. Fred Cromes, Jr., Ph.D.

"The Rehabilitation Counselor, with appropriate and thorough training in cancer can have a significant impact on cancer patient employers and potential employers. If the Vocational Rehabilitation Counselor maintains regular and close working relationships with cancer centers and the American Cancer Society in their areas, the improvement of vocational rehabilitation services and total services to cancer patients is inevitable."

Excerpts from comments by Judy Spolum, M.S., CRC

STATEMENT OF PROBLEM

With the advent of new modalities for the cure and containment of cancer, greater numbers of individuals are living longer and thus having to cope with the side effects of treatments, their own and families' psychosocial response to illness, return to employment and the community-at-large in terms of its response to the "cancer victim". Public and professional recognition of the need to do something about the disease that is the second leading cause of death in America was translated into action by the enactment of the National Cancer Act in December, 1971. One goal of this Act was to develop in its cancer control programs directed toward rehabilitation of treated patients to as nearly normal a state as possible. Yet the barriers to fulfilling this goal still persist. One of the primary barriers is the lack of knowledge about cancer by those dealing with the people who have the

disease. To achieve this goal there must be major shifts in the Attitudes, Beliefs and Commitments by health care providers and vocational rehabilitation counselors from one of "what's the use?..they're going to die soon" to a recognition that many more persons than are now evident can be placed in a vocational rehabilitation program.

The National Cancer Institute recognized that "The problem central to effective social and vocational rehabilitation is one of attitude - on the part of the patient, physician, his family, friends, employer; on the part of the general public; and the health professions."(1) If the belief is present that rehabilitation is possible, then the commitment to develop an action program usually follows. A concentrated application of these ABCs by the health care professions will result in a significant lowering of the barriers to full rehabilitation of the cancer patient.

As a result of my personal experiences and a summary review of the literature dealing with cancer and employment, I find that the primary reasons for a low level of cancer patient involvement in vocational rehabilitation programs are: 1) the lack of updated information on the care, treatment and prognosis of the disease on the part of those engaged in vocational rehabilitation; 2) the lack of an aggressive and consistent educational program directed toward the health care and rehabilitation professions on the rehabilitation potentials of persons whose cancer has been cured or contained, and, 3) the lack of consideration of rehabilitative and vocational goals early in the treatment planning for the individual.

In 1974, the Federal-State Program of Vocational Rehabilitation served 1,152 persons with malignancies, of which 286 were designated as being rehabilitated.(2) In my opinion this number is too few, given the number of newly diagnosed cases occurring annually. In the same year, the American Cancer Society reported that 665,000 persons were diagnosed as having cancer.(3) A crude adjustment for age and stage of disease would leave 200,000 considered to be eligible for employment. If only 10% of these (20,000) were appropriately evaluated, we would realize the goal of insuring all persons with this greater opportunity to be considered for vocational rehabilitation services.

Two findings of a 1977 Mayo Clinic study on cancer patient discrimination are applicable to this assumption, namely:

Finding #1...Cancer patients are not being made aware that they might be eligible for vocational rehabilitation services; and,

Finding #2...The Vocational Rehabilitation Act of 1973 has not had a substantial impact on the rehabilitation of cancer patients.(4)

The problem of why there isn't earlier consideration of vocational rehabilitation goals and/or their being made a part of the treatment plan which evolves at the time of diagnosis, may be found in the absence of input by the patient, rehabilitation staff, social workers and vocational counselors. (5)(6)(7)(8)(9)(10) This condition becomes the barrier to the broader involvement of the community-at-large and employers specifically.

Because public education programs are primarily geared to imparting information on the early warning signs of cancer; the advantages of early treatment; and the value of preventive health measures such as not smoking and screening-detection programs, there is little recognition by employers, labor unions or the community that persons who are cured or are in a stage of cancer containment have an improved health status to the point where they are able to return to work or are excellent candidates for vocational rehabilitation counseling and will be able to live long productive lives.(11)(12)(13)

HYPOTHESIS

Through a system of Program Cooperatives, a cancer action program involving the patients and their families, selected community medical and rehabilitation organizations, health care professionals, employers and their respective trade associations, labor unions, legislators and their aides and citizen leadership, it would be possible to increase the cancer knowledge level of these groups to the point where the following objectives would be achieved:

1. Earlier integration of vocational rehabilitation considerations into the person's treatment plan, e.g. at the point the treatment plan is developed;
2. Significantly more persons being referred for Vocational Rehabilitation (V.R.) services; and,
3. Affirmative action being taken by the community-at-large and employers in reintegrating into the workplace those persons who have or had cancer.

The educational message content would include: 1) diagnostic and treatment information; 2) relevant prognosis studies; and the relationship of objectives 1 and 2 to the vocational rehabilitation aspects of the person's treatment plan.

ACTION PLAN

The development of the Program Cooperatives (PC) can be the means by which the education action programs will eliminate the barriers to community participation and employer involvement in programs designed to create an environment where the cancer patient can move easily into the mainstream of economic life in America. Barriers to these program objectives have been identified from the literature and the empirical evidence gained by the author in his twenty-five years of expeirence working with the chronically ill. Because cancer is considered a chronic disease it can provide an excellent paradigm for developing results oriented action programs that will remove the barriers to the patient's full recovery.

Program Cooperatives can be described as a fragile community organization structure having its genesis in the interface of community institutions, organizations, and professions who have arrived at a stage of community development where there is agreement to work together. The ingredients that nurture the evolution of this process and markedly increase the chances of achieving mutually agreed upon objectives can be found in the interpersonal, organizational and operational relationships that exist between the participating groups and individuals. Program Cooperatives, as a concept, are indigenous

to any action program designed to maximize the impact of community resources on the problem. Essentially, it is designed to facilitate action at the community level in a cooperative and collaborative manner with open lines of communications. Program Cooperatives are those organized, planned, and implemented programs and activities mutually agreed upon by the participants engaged in a consortium of community organizations. Cooperatives by definition are marked by a willingness and ability to work with others.

Health care providers are now being encouraged to utilize existing and pooled manpower and fiscal resources as one approach to reduce this cost of health care in the United States. One means to this end in cancer rehabilitation is Program Cooperatives that are organized to reduce costs resulting from health problems.

Implementing the concept of a PC has been demonstrated through the Metropolitan Detroit Cancer Control Program, where an array of community medical care institutions, the Michigan Bureau of Vocational Rehabilitation (BVR) and employers have created a working arrangement whereby, in the course of two years, there has been an increase in the number of cancer patients receiving rehabilitation services. This arrangement demonstrated that a positive attitude about cancer can be developed; a belief in the concept of rehabilitating the cancer patient; and a commitment to participate in a demonstration program to field test the idea. The medical institutions and organizations involved included the following: 14 clinical demonstration hospitals serving the Metropolitan Detroit area which through the course of a year diagnose and treat approximately 50% of the area's cancer cases; the American Cancer Society through its public, patient, and professional educational programs providing necessary linkage to these target populations; the Michigan Cancer Foundation through its extended continuing care and rehabilitation services provide the critical follow-up support services to the patient at home and as a linking agent back into the mainstream of community life; Wayne State University College of Medicine through its coordinating support services and the development of cancer patient management criteria documents which identify the continuing care and rehabilitation needs of the patient to provide for pre-discharge planning the incorporation of these services. This PC provided the link between the patient, the professions, BVR, and the community which includes employers. In 1975, the Michigan BVR reported two cancer cases in the Detroit area. Following an intensive inservice training program of selected members of their regional staff on cancer, its etiology, diagnosis, treatment and rehabilitation potential, there occurred a steady increase in the number of persons accepted for rehabilitation counseling and in 1977 over 200 had clients with cancer who received service. So successful was this approach that the Revion V Office of Vocational Rehabilitation (DHEW) short-term training grant was secured to implement an expanded version of the Michigan Plan in this region. In January, 1978, a four-day Vocational Rehabilitation short-term trainig course "Cancer and Employment: A Vocational Rehabilitation Perspective" was successfully held in Detroit. The result of the pre- and post-tests, program content assessments by participants and current follow-up reports indicated that there was an increase in the knowledge of cancer, a more positive attitude about the disease and a commitment to implement similar inservice training programs in three of the Region's states.(14)

This action program in Michigan has its origin, in part, in the recommendations of the 1972 series of conferences on the rehabilitation of the cancer patient sponsored by the National Cancer Institute, Division of Cancer Control and Rehabilitation (DCCR). A series of recommendations evolved from these meetings and led to the funding of several million dollars (from 1973 through 1977) by DCCR of programs designed to increase the activity in the rehabilitation of cancer patients. These recommendations focused on:

- Education programs designed to transmit the known knowledge about cancer; the potential for rehabilitation of cancer patients; and the employability of the cancer patient. These education programs were targeted to the patient, their families and friends, general public, employers and the health care professions inclusive of vocational rehabilitation counselors.(15)

- Vocational rehabilitation, in fact all rehabilitation, should begin at time of cancer diagnosis. Thus it is imperative that rehabilitation planning begin at this point and not be delayed until an arbitrary time period after treatment.

- Industrial medical directors and personnel executives should be informed of this health and work experience and encouraged to give consideration on an individual basis to each patient treated for cancer and seeking employment. An educational program along these lines could be offered on a company or organizational basis (e.g. Industrial Medical Association, Academy of Occupational Medicine, Administrative Management Society).

- Early and continuous contact with the employer should be maintained before the image of the worker as a human being becomes blurred, and he becomes a "cancer case."

- Although preliminary studies have shown that cancer patients can be rehabilitated faster and with less cost than some other disability groups, most state rehabilitation agencies have not recognized this fact.

- All restrictions which currently disqualify the cancer patient from receiving rehabilitation services should be removed, and each patient should be considered on his own individual prognosis and merits.(16)

The opening of access routes to the community to further reduce the barriers to the employment of the cancer patient would require many of the same strategies. The employer is but one of the many publics that an action program is designed to reach. The barriers to community resistance must be reduced to provide a more ready access to the individual who has recovered from his cancer or is in remission. These publics include:

- Relatives and friends
- Health care providers inclusive of physicians, nurses, social workers
- Rehabilitation Counselors
- Insurance carriers
- Governmental programs such as Supplemental Security Income (SSI), Workmen's Compensation

- Labor unions and their members
- The public at large

As an action plan begins to be formulated, reliance on the mass media alone to be the battering ram against the barriers is not sufficient. Several approaches are required and should be tailored to the specific publics. Griffiths points out that:

> "The mass media can be effective in giving individuals correct knowledge, but personal contacts, especially those that reach individuals in small groups, help to actualize the next step by providing the setting and stimulation for individuals to change old health practices or to adopt new ones. Believing that mass media alone can do the job for health education, or that the imparting of health knowledge is sufficient, is a very unrealistic and simplistic approach."(17)

An action plan must be designed to achieve maximum involvement and impact on the problem. Through the PC we can effectively implement the recommendations of the Mayo Clinic Study and the National Cancer Program, Rehabilitation Panel which are as follows:

Mayo Clinic Study (4):

> "Recommendation #1 -- Increased emphasis on providing services to cancer patients should be undertaken by state vocational rehabilitation agencies. (p. 93)
>
> Recommendation #2 -- Physicians should assume a more active role in referring cancer patients to sources of vocational rehabilitation. (p. 94)
>
> Recommendation #3 -- State vocational rehabilitation agencies should reassess the medical criteria used in evaluating cancer patients. (p. 94)

Recommendations from the National Cancer Program (15):

- "...the patient and family must be recognized as having full rights in the partnership with professionals for the therapeutic and rehabilitation efforts.
- The development and expansion of patient and family education programs in conjunction with professional practitioners providing cancer rehabilitation care.
- In the area of public education, the consensus of the panel was that the diagnosis of cancer is presently associated with a sense of hopelessness, fear and despair by the patient, his family and the general public. This image must be modified to one of hopefulness and the reality of opportunity for an improved quality of life. It was agreed that a broad-based educational and informational program is critically needed to modify the image. The new image should be communicated to the hard-to-reach populations, industrial employers, insurance agencies, clergy, and community organizations."

The action plan objectives are designed to:

1. Institute inservice educational training efforts through seminars, workshops, and special meetings designed to inform health care professionals about cancer, its etiology, and motivate them to include rehabilitation and vocational action employment programs in their treatment regimens with a greater involvement of the cancer patient;

2. Utilize professional journals, house organs, newsletters, and other similar vehicles for communicating to the target publics;

3. Prepare succinct cancer information, case examples and data on accomplishments of rehabilitation efforts. These should be custom designed for the selected target populations in terms of scientific data and research-oriented material for the health professions, impact information on the overall problem and what is being done to meet it for the public at large;

4. Plan year-round activities through the PC to reach the target populations is a basic overall approach. Without the development of an integrated plan using the suggested multiple modalities for accessing the publics, the program becomes spasmodic and will ultimately abort through the lack of continuity and follow-up being built into the operation.

5. Periodically evaluate the achievements of the program objectives. This provides data for the management decisions on whether to maintain the current program effort; increase or spread one or more activities within the program that are achieving results; whether to terminate an effort because of a lack of impact or to redesign an activity predicated on changing needs; community target populations' moods; etc., and refer certain aspects of the overall plan to other agents in the community who are more appropriate to carry out that activity.

Instituting a systems approach to the conceptualization of the planning, implementation and evaluation process is being suggested. A modified management by objectives approach is suggested as the planning tool.

The Bureau of Vocational Rehabilitation Services of the State of Michigan is a case in point in terms of using of inservice training programs directly related to technology and information transfer to a target population.

Employer attitudes and beliefs about cancer can be changed and their commitment to an action plan for cancer patients can be secured if they know the facts. The Metropolitan Life Insurance Company, in reporting on their experience on re-employing the cancer patient, found that:

. "...their performance differs little from that of others hired at the same age for like assignments. Company expense was not noticeably increased by excessive absences, reduced productivity, or increased mortality.

- All applicants must pass a medical screening; knowledge of this requirement may have discouraged applicants with a cancer history from applying for employment.

- During the period of the study, the acceptance rate of such applicants increased as the Medical Division gained experience.

- Survival for five years after treatment without recurrence or metastasis strongly favors acceptance. If less than five years have passed since treatment, the Medical Division is guided by recent studies of survival rates achieved by specific courses of therapy.

- Of the 34 who were discontinued, about one half left in the first six months of employment. Only two of these persons were discontinued for health reasons; one retired, and 28 voluntarily left the company. It was felt that the turnover rate of those with a cancer history was about the same as that for comparable employees of the same age.

- Compared with other employees of the same age, records of turnover, absence and work performance were satisfactory.

- It can be concluded that selective employment of such persons in positions for which they are physically qualified is sound industrial practice." (18)

Wilson, et al, in another study on employment and the cancer patient reported:

- "The finding that 80% of the respondents who had a pre-cancer job were still working for the same employer at the time of the survey is a demonstration of the stability and security of employment in our sample.

- The majority of cancer patients employed since treatment reported their return to work had been eased by one or more special arrangements made by their employer.

- Recommendations

  1. Continued efforts in this area should concentrate on the effective dissemination of information on cancer and employment. The research indicates that practical information on cancer and employment is particularly needed by three kinds of individuals: by industrial physicians, by those recovered cancer patients who are disadvantaged in seeking employment because of a lack of job skills and experience, and by those who counsel and advise such individuals.

  2. A professional seminar on cancer and employment should be held for industrial physicians.

  3. Facts on cancer and employment of special practical relevance to employers should be presented in an information booklet." (19)

Potter in reporting on his successful treatment of cancer patients states:

- "Although no hard data are available on the subject, the common experience is that discrimination does exist in the employment of patients who have had cancer. In many circumstances, the patient's prognosis is excellent, and such disqualification from work is a financial and psychological disaster for the patient and his family.

- The demonstration that rehabilitation and retraining costs are repaid economically dozens of times over must cause us to redouble our efforts to allow the cancer patient to return to productive work. What statistics are available demonstrate that the selective employment of the cancer patient is a good management practice, in addition to being of humanitarian and psycho-social value and of benefit to society.

- A goal should be established to return all cancer patients who are physically able to productive work.

- Cooperative action here is desirable, for it is in the best interest of all parties." (20)

Koplin in reporting on "The Implications of Cancer for the Labor Union" stated:

- Ten years ago the national cost of lost earnings, disability and premature death due to cancer, combined with the value of care received totalled 2.6 billion dollars. Today Dr. Ainsworth of this panel places this cost near 15 billion dollars.

- Perhaps workers with malignancy or a history of malignancy should have equal employment opportunity.

- It is suggested that professionals like ourselves devote additional efforts toward the further involvement of management, labor, voluntary organizations, and government in improving health, erasing the stigma of cancer which prevents employment, and eventually eliminating occupational cancer." (21)

In summary, it would appear that the problem of reemployment is more a matter of the lack of an affirmative action plan being instituted by the physician initially and supported by follow-up work of health care teams including the VR counselor to insure that all employable persons are back on the job. Gambrell stated:

> "Why are employers so reluctant to hire ostomates? Discrimination would appear to stem largely from a lack of information about ostomy among employers, personnel managers, and perhaps company physicians and nurses." (22)

Stone adds to the physicians' point of view to the employment of cancer patients by stating:

"Provided with a realistic prognosis on a recovered cancer patient, his opportunity for joining the work force is greatly improved over what it has been. There is no practical reason why, for example, the recovered Hodgkin's patient with a life expectance of 10 to 15 years should be denied job placement." (23)

The suggested educational program should be designed as a "soft sell" but with consistency in terms of year-round implementation, built in follow-up and evaluation. Once-a-year campaigns to employ the handicapped, periodic inservice seminars or speeches will not provide the continuity of effort or the research data on program benefit and effectiveness. There appears to be a feeling by those dealing with this problem that employer resistance is not the principal cause but is one of medical-patient conscious involvement in rehabilitation, vocational and reemployment programs. The Mayo Clinic study recommended that "an extensive program to combat employment discrimination is not warranted." (4) In addition, Wheatley, et al, concluded that, "the selective hiring of persons who have been treated for cancer, in positions for which they are physically qualified, is a sound industrial practice." (24)

Instituting an affirmative action program for employing cancer patients could be accomplished by reaching employers through the PC since they are a part of the community and not apart from it. Therefore, when developing the inservice programs, the access routes to the employers would be through:

- Individual large employers
- Trade Associations
- Employer Associations
- Personnel Managers Professional Group Associations
- Chambers of Commerce
- Service Clubs where traditionally there are significant members who are employers.
- State and local governmental business development corporations whose advisory groups are made up of the employer groups in the community.

Community cancer information could be communicated through publications and mass media such as:

- Trade Association Magazines and Newsletters
- Professional Management and Personnel Journals, Magazines,and Newsletters
- Employer House Organs
- National magazines geared to business and industry
- Governmental publications at the state, local, and national levels
- Radio and television features such as interviews and spot announcements
- Weekly and daily newspaper features
- Health and welfare organization newsletters and publications that are sent to employers

The Program Cooperative would include the following major groupings of participants in an employer action program.

- Employer groups
- Labor unions
- Rehabilitation and health care professionals
- Communications specialists from advertising and media

Integral to the educational program will be deliberate planned involvement of the patient self-help groups. They provide a most important link in the resocialization chain of events directed toward the individual's return to society. While all cancer patients may not need this support, it is self-evident that many do given the existence of the self-help group. Groups such as Reach to Recovery; Make Today Count; Lost Cord; Ostomy Association; etc. are excellent resources for the health care professional to tap into and utilize in the education and rehabilitation process. However, this can only be accomplished where there is mutual respect and willingness by the professionals to recognize and accept the contribution of the self-help groups. There is a need for "us" the professionals to listen and learn how "they" the patients conquered the various problems they faced. Powell states:

> "...potential uses of the self-help group which should be kept in mind are, 1) A professional may use a self-help group as a source of information about the potentially supportive community available to a particular client. In this format, key members of the self-help group operate as consultants to the professional for the purpose of identifying social opportunities and discussing issues of concern to the client." (25)

Frequently community and family attitudes toward the handicapped person present difficult barriers for that person to overcome. How to cope with this is many times overwhelming to the patient. Dixon states:

> "These populations face special obstacles in their efforts to maintain a normal network of satisfying social relationships and these obstacles go beyond those which derive directly from the medical conditions and from resultant activity restrictions, and they may have serious consequence on life chances in several realms (social, vocation-economic, medical)." (26); and "While a few words may suffice to indicate the value derived from the participation of people who have successfully overcome their problem, a thousand words cannot convey the impact made by the person who is a living demonstration that problems can be overcome." (25)

IMPLICATIONS

The implications for this suggested approach to program development, service delivery and research are as follows:

1. The need to move toward a more aggressive and earlier application of current knowledge of cancer rehabilitation into the treatment plan;

2. Encouraging greater inter-organizational efforts through "Program Cooperatives" in order to systematically deal with the problem from the point of diagnosis through rehabilitation in a more effective and efficient manner;

3. Developing a climate and readiness where the health care and rehabilitation professions approach the various elements of the problem as a team; and

4. Designing innovative clinical research protocols that will neither destroy or dramatically alter the focus of the program nor be so costly as to discourage scientific review.

With respect to legislative implications it would appear that with the present National Cancer Act and its nearly one-billion dollar budget, the Vocational Rehabilitation Act of 1973 and its amendments, and various insurance coverages, further action in this area is not indicated. The mandated agencies know what has to be done and may need increased funding or a reallocation of existing funds to accomplish the job. Employment practices with respect to cancer patients do not require legislative action at this time. However, more evaluation and research of the problems may result in recommendations for some form of legal assistance.

CONCLUSIONS

> "An obvious prerequisite for any program of cancer education is that facilities should exist for the prompt handling and treatment of those who respond to the educational message." (27)

This statement by Davison puts into perspective the question of: Are there sufficient community resources to manage a dramatic increase of clients into the program? I submit that all the necessary components to implement such a plan exist and need only to become engaged. My assumption is predicated on the following: 1) the difficulty in projecting with any reasonable accuracy the potential number of individuals who would enter the program and, therefore, fears of overloading the system are unfounded; and 2) the nature of the educational process is such that over time (2-3 years) there would be a gradual increase of people in the system thus allowing for planned changes and/or increases in resource allocation to accommodate the increase.

By instituting the Program Cooperative concept as a community outreach effort, it will create the ambience within which the framework for implementing the educational effort is made possible. This in turn should act to reduce cancer morbidity and foster rehabilitation of the client with cancer.

REFERENCES

1. The Strategic Plan. National Cancer Program. Department of Health Education, and Welfare. January, 1973

2. Information Memorandum. Department of Health, Education, and Welfare, Office of Human Development, Rehabilitation Services Administration. June, 1976. RSA-IM-76-87

3. Facts and Figures. American Cancer Society, 1975.

4. A Study of Discrimination Toward Cancer Patients, By Insurers, Employers and Vocational Rehabilitation Agencies. The Vocational-Insurance Committee, Mayo Clinic Cancer Rehabilitation Program. October 1975.

5. Rehabilitation of the Cancer Patient. Geriatrics, March, 1970. p. 158

6. Trachtenberg, J. Social and Occupational Rehabilitation: Concern With the Patient, Family, and Community. Paper presented at Boston University Medical Center, June 6, 1973. p. 6-7

7. Healey, J. E. Role of Rehabilitation Medicine in the Care of the Patient With Breast Cancer. American Cancer Society, Professional Education Publication, 1971. p. 11

8. Fried, D. Rehabilitation of the Cancer Patient. Cancer, Vol. 36, No. 1 July, 1975. p. 277-78

9. Dietz, J. H. Rehabilitation of the Cancer Patient. Medical Clinics of North America, Vol. 53, No. 3. May, 1969. p. 4,6,9

10. Harper, B. C. Social Aspects of Cancer Recovery. Cancer, Vol. 36, No. 1. July, 1975. p. 276

11. Ainsworth, T. A. The Cost of Cancer. Cancer, Vol. 36, No.1. July, 1975. p. 283

12. Dahle, C. Mass Communication: Newspapers, Magazines, Broadcasting In: Health Education Theory and Practice in Cancer Control. Geneva International-Union Against Cancer. 1974. p.97

13. O'Neill, M. P. Psychological Aspects of Cancer Recovery. Cancer, Vol. 36, No. 1. July, 1975. p. 271

14. Cancer and Employment: A Vocational Rehabilitation Perspective. Report to Region V Office of Vocational Rehabilitation, Department of Health, Education, and Welfare. April 20, 1978.

15. National Cancer Program. Department of Health, Education, and Welfare. Cancer Program Objective 7, Rehabilitation Panel 6 Education. December, 1972. p.1-3.

16. National Cancer Program. Department of Health, Education, and Welfare. Cancer Program Objective 7, Rehabilitation Panel 5 Vocational. December, 1972.

17. Griffiths, W. Health Education Definitions, Problems, and Philosophies. In: Health Educ. Monographs, Vol. 31. 1972. p. 10-11

18. Employing the Cancer Patient. Metropolitan Life Insurance Company, New York, New York. Statistical Bulletin, June, 1973

19. Wilson, T., Bercini, D. H., and Richards, J. A. A Study of the Employment of Work-able Cancer Patients: Volume II, Survey of Cancer Patient Employment Experiences. Human Resources Research Organization, Alexandria, Virginia. December, 1976.

20. Potter, J. F. Summary Statement Concerning the Successfully Treated Cancer Patient. Cancer, Vol. 36, No. 1. July, 1975. p. 304

21. Koplin, A. N. The Implications of Cancer for the Labor Union. Cancer, Vol. 36, No. 1. July, 1975. p. 292-94

22. Gambrell, E. Employment of the Ostomate-Well-Adjusted, Healthy Ostomates Are Fully Employable. Ostomy Quarterly, Vol. 8, No. 5. Fall, 1971. p. 1

23. Stone, R. W. Employing the Recovered Cancer Patient. Cancer, Vol. 36, No. 1. July, 1975. p. 285-86.

24. Wheatley, G. M., Cunnick, W. R., Wright, B. P., and Van Keuren, D. The Employment of Persons with a History of Treatment for Cancer. Cancer, Vol. 33, No. 2. February, 1974. p. 445.

25. Powell, T. J. The Use of Self-Help Groups as Supportive Reference Communities. Amer. J. Orthopsychiat. 45(5). October, 1975.

26. Dixon, J. K. Coping with Prejudice: Attitudes of Handicapped Persons Toward the Handicapped. J. Chron Dis, Vol. 30, No. 5. p. 307-322.

27. Davison, R. L. Special Considerations in Cancer Education Programmes In: Health Education Theory and Practice in Cancer Control. Geneva, Internation Union Against Cancer. 1974.

CHAPTER 2

CANCER: ACTION FOR IMPROVING SOCIALIZATION AND FAMILY SUPPORT, AND REDUCING STIGMA AND NEGATIVE ATTITUDES

Author: Melvin J. Krant, M.D.

"The attitudes of the general public and the health care professional greatly influence the response of the person with cancer to his disease. Dr. Krant's paper was particularly useful in a review of research completed on the cancer patient's response to his/her disease. It is obvious, however, that for the cancer patient, his family and significant others, the cancer does not 'feel' hidden or remain hidden in light of other relationships. The word, cancer, carries connotations that are totally negative despite statistics to the contrary.

The Rehabilitation Counselor and other health care professionals, if well trained in the medical, psychological, social and vocational implication of cancer, and if involved in the rehabilitation team within a hospital setting, can assist in changing the negative patterns of the person facing cancer.

Psycho-social evaluation of all cancer patients at initial contact with the Oncologist would assist in determining a more complete picture of the cancer patients' psycho-social needs.

Self help groups (with professional assistance) need to be increased and supported both financially and verbally by the health care professionals. Patients with cancer should have assistance in locating such programs and be encouraged and referred to such groups in their community.

The cancer patient and the health care system are deprived of complete care, if planning is not provided for vocational rehabilitation services for this patient."

Excerpts from comments by Judy Spolum, M.S., CRC

"Vocational rehabilitation of the person with cancer involves that person moving from point A (diagnosis and treatment and reaction to those events) to point B (recovery and adptation to normal living at some level). The factors influencing this movement can be divided into those intrinsic to the person who has cancer (attitudes, coping strategies, self concept, etc.) and those that are extrinsic (attitudes of family, friends, health care personnel, the world of work, etc.). Dr. Krant has described in considerable depth the role of this set of factors in the reactions and potential rehabilitation of the cancer patient. He has emphasized the intrinsic, and in my opinion the more important, factors but has not ignored the significant importance of the patient's support system of health care personnel and family.

"An additional comment relates to rehabilitation program development in cancer. The support necessary to develop programs will depend upon adequate evaluation, i.e., if there is a payoff, the money will be available. The most significant evaluation issue is the lack of a generally agreed upon, reliable and valid, rehabilitation outcome criterion measures. This should also be suggested as a genuine research need. All the education, attitude change, and innovative treatment and counseling in the world means nothing to this rehabilitation effort if effectiveness cannot be or is not demonstrated."

Excerpts from comments by G. Fred Cromes, Jr., Ph.D.

Among the varied definitions ascribed to the word "handicap" by Webster is "Any disadvantage that makes success more difficult". The cancer patient often finds himself in just such a predicament, not only as he faces the question of getting on with his life as a social participant, but also as he faces himself and makes conscious and unconscious judgment as to his worth. The gravity of the problem, in terms of the inner-directed lives of those involved, is encompassing and depthful. I will try to elucidate certain dimensions of the existential impact brought by the diagnosis of cancer to many of its bearers so that the handicap is not conceived of as only a social inconvenience. The problem is in the personhood of the individual.

In a paper entitled, The Price of Survival of Cancer Victims, published in 1970, Morton Bard, (1) a clinical psychologist formerly at New York City's Memorial Hospital for Cancer and Allied Diseases, described the cancer patient as.. 'a person under a special and severe form of stress'. The diagnosis of cancer, as does the diagnosis of any seriously perceived disease, disturbs life long patterns of behavior that individuals have employed to 'get-on' with life. But in addition, Bard argued, cancer is perceived by most people as an always fatal, particularly loathsome disease, which carries the weight of disability, recurrence and repeated threats of death. Indeed, in the common parlance of the English language, the word cancer is employed to describe something evil, dirty, destructive, malignantly offensive, and ravenously consuming. The American involvement in the war in Vietnam was seen, by many, as a cancer eroding the worth of the nation, as well as the confidence of the people in the government.

From childhood onward, an individual painstakingly organizes a system of beliefs, designs and behaviors in order to bring his physical, emotional and social needs into harmony with the demands of his environment. As social creatures, the psychological make-up of men and women are subject to the constraining forces of the culture to which they belong. Harmonizing is to blend into, and seek recognition from, the community of people that an individual relates to, be they spouses, children, neighbors, friends, co-workers, townspeople, co-religionists. An individual, in this psychosocial sense, is invested in others, and in return is invested into by others. The greater the emotional investment a person has to another, the more charged is the meaning

of his life in terms of the other. Investment seems to be made both to give, as well as to receive, nurturance in the form of support, love, self-worth, self-esteem. These investments are made through being... being in the body and in the personality. Madison Avenue commercialism has long been aware that the way to sell a product is to link it to attractiveness in the body, self-valued status in the community or value-ranked to a significant other or others. Thus the 'I' of a person is linked intimately to the body, and specifically to those parts of the body that carry the most 'value-weight' for definition of the self. Characteristics of the body play an elaborate role in defining the good and worthy self to the individual, and in return, to the way he conceives that others must value him. It should not be difficult to grasp the essential that self-worth and self-esteem are placed under great strain when cancer is diagnosed, not only for the inherent mortal threats of the disease itself, but because of the sacrifices frequently demanded of the 'worthy' body in order to effect therapy. Cancer as well as cancer treatment, frequently mutilates the intact body, and thus 'damages' the cherished investment that the individual has made in this ego-citadel. The body as an instrument of power in personal relationships may become 'damaged goods', with marked reduction of personal self-esteem.

The extent of this disorganization is related to the body part involved, to its valuation, and to adaptive (compensatory) personality qualities of the individual. The age, social position and the sense of past and future help define how an individual will respond to the diagnosis and to the impact of therapy. For cancer happens to people who have a past developmental history, and a sense of the future. Cancer impacts on an individual who is somewhere in the arc of a life career, in which ambitions, responsibilities, life tasks and postponed gratifications exert an influence in defining an individual's outlook in the wake of the disease. And since an individual is strongly influenced by his culture's implicit (and often explicit) viewpoints of an issue, bearing cancer may imply something different, depending on which social group the patient relates to.

The existential impact of the disease, and required therapy, is therefore related to three basic postures: a) a person's psychological organization, and investment in the afflicted body part; b) a person's cultural and social organization, and the nurturing investment with other people; and c) the position of an individual in the arc-moment of this career in lifetime. Obviously, the impact of cancer is also differentiated in terms of the stage of the illness as regarding the possibility of cure or of terminality. For the person in the early stages of cancer, when cure is possible and promising, the impact is quite different than it is for the patient with recurrent disease, as it is for the patient with terminal disease. For the purpose of the paper, I will deal only with the potentially curable, or early advancing stages of cancer, where the actuality of dying is quite distant.

The meaning of cancer in terms of the specific body-organ involved can best be understood by examining two body regions that have been reasonably studied. Breast cancer has probably received the most attention in this regard, although even in this province, studies have only recently been conducted that have focused on the adaptability of women to both the meaning of cancer and to the meaning of mastectomy.

In the nineteenth century, several physicians made the observation that cancer appeared in melancholic, grievous women who appeared to have suffered significant reversals of life fortunes, especially in regard to human relationships. These observations were totally unsystematic, were not 'controlled' in anything resembling a study fashion, and were seldom spelled out in psychological detail. While for this paper's purposes, adaptability is not the same phenomenon as causality, in fact the two conceptualizations may be linked, for if there were psychological causal factors in breast cancer development, we might expect that these same factors would influence the manner in which an individual adapted to the consequences of the illness.

In the 1950's, several papers appeared that attempted to appraise causal factors in psychoanalytic terms. Tarlan and Smalheiser (2), and Bacon, Renniker, and Cutler (3), stressed that breast cancer appeared in women with significant conflicts in sexual identity, with mother-daughter conflicts, and with unresolved life-developmental hostility. LeShan and Worthington (4) describe the impoverished human nutrient world of people who develop cancer; Bahnson (5) postulated a theory of repression of conflictual psychological material as the basis for cancer evolution. I will not deal further with this material, but a reading of the literature may be useful.

As for adaptation, systematic studies are few, although those available seem quite significant. A fair amount of case histories and anecdotal reports do exist. For example, reporting in 1955, Bard (6) noted that for some women, losing a breast was interpreted as a worse assault on their integrity than was the fear of death associated with cancer. Many of the patients that he worked with, he argued, were convinced that a deformed disfigured person was held in low-esteem by the community at large. Such conviction led these patients to feel that they could only expect pity, revulsion, intolerance, or some equally disturbing reaction from people in general. Bard gave no statistics to indicate how many women with breast cancer experienced such reactions, nor what the pre-morbid social and personality factors were that might foster such responses. How to recognize pre-operatively women who would experience such a reaction was not discussed, nor were these reactions examined in terms of the length of time they persisted, nor how and whether they actually interfered with a person's functional adaptation after discharge from the hospital. Bard did not comment on what might professionally be offered to help such individuals feel better about life.

In 1973 Ervin, a surgeon, (7) argued that emotional suffering appeared to far outweigh the physical pain in women who had undergone radical mastectomy. He specifically addressed the problem of the breast as psychosexual symbol, and discussed the feelings of mutilation and defeminization that some of his patients suffered as a result of mastectomy. He noted that three of his patients committed suicide as a result of perceived rejection by husbands or lovers. Again, specific research questions, in a given sample of breast cancer patients, were not addressed.

Quint (8), in a year-long study of 21 middle-aged, middle-class women who underwent radical mastectomy, observed that the fear of recurrence, and feelings of doom, were interlocked with the sensations of defeminization and mutilation,

and that such feelings were persistant, or recurrent, during the entire year following surgery. For most of her subjects, the mastectomy was not considered a cure. Instead, the patients interpreted the operation, despite the lack of recurrence, as a warning sign of impending death. For the women in the study who had delayed wound healing, these feelings of doom were intensified. Quint found that a number of these women (unspecified) had considerable troubles in getting back to functioning again, be such function taking care of their homes, or working on the outside.

A recent publication from England has reemphasized the adaptive problems experienced by post-mastectomy women (9). Of 196 mastectomy patients observed, (the extent of mastectomy, radical or simple, was not stated), short-term effects were clearly marked, and 56% of the patients were judged to have experienced considerable emotional difficulty in the post-operative period. Half of these difficulties were estimated to be of psychiatric proportion. These patients overtly worried about breast prostheses, about attitudes of their husbands or partners, about their new shapes and scars, and about their ability to face other people when they returned home. Long-term effects were also considerable. In this study, in which breast cancer patients who underwent mastectomy were interviewed in their homes during the year following amputation, and were compared to a similar age and social-class matched cohort of women who were being followed for benign breast disease (non-mastectomy), Maguire indicated that by the end of the post-operative year, mastectomy patients experienced a 20% incidence of depression (as compared to a 5% incidence in the benign group); a 28% incidence of sexual difficulties (3% for the benign group); and a 44% incidence of difficulty in coping with work (3% for the benign group). Maguire did not sort out the relative weight of the diagnosis, as compared to the weight of the mastectomy, on the patients' persisting problems.

In another publication, Jameson, et al, (10), interviewed 41 post-mastectomy women with an open-ended questionnaire, and with several psychological test instruments. The mean post-surgery study time was ten months, and 98% of the sample had undergone a radical, or a modified radical, procedure. Although 83% of the sample indicated that their emotional adjustment was good or excellent, 25% indicated that they had had suicidal ideation after mastectomy, and 15% had sought professional help for emotional problems related to the surgery (an undetermined percentage of the patients were already in psychotherapy prior to surgery, and had that resource available to them as part of their support system). Thirty-six percent of these patients reported a greater, or a much greater, use of tranquilizers after mastectomy, and 15.5% reported that their alcohol intake had increased significantly. A quarter of the sample felt that their sex lives had deteriorated significantly due to the operation. Women over the age of 45, with long and stable marriages seemed to fare better in emotional, social, and sexual adaptation, than did younger or presently unmarried women. The importance of the sexual partner, husband or lover, as a source of support to these patients, could not be overstated, Maguire felt, although specific partner behaviors were not elicited.

In a recent review, Asken (11) makes a rather universalizing statement that for the younger patient, a mastectomy forces confrontation with mortality, while for the older women, the operation confirms the debilitating effects of old age. While this generalization is not given statistical verification, empirical observations confirm the potential of these responses. For either group, post-surgical complications, such as the development of lymphedema of the arm (fortunately a not too frequent post-operative consequence) is of great concern to those afflicted, and inhibits rehabilitation to social function. Asken also reviewed a slowly growing literature on the value of reconstructive mammoplasty as a psychological adapting procedure. The consequence of offering, and having available, a mammoplastic operation that provides a simulated permanent breast has been declared by some as mandatory for women, although long-term studies on the adaptational value of the procedure have not been done.

In a third relatively recent study, again from England, two-year adjustment to simple mastectomy, rather than radical or modified radical, was reported. 30% of the patients showed continued psychological stress even after two years following surgery. Nor was the course of recovery smooth for those who eventually did. Morris, et al (12), found that patients who were apt to have depressive symptoms one to two years after surgery, had been recorded to have clinical or psychological test indications of depression immediately prior to surgery regardless of their previous psychiatric history. They also found that patients likely to have long-term sexual difficulties were perimenopausal at the time of surgery. Various pre-surgical psychological tests were administered, and patients who scored high on the neuroticism scale of the Eysenck Personality Inventory were likely to remain stressed for a long period of time after surgery. Morris, et al, reiterate in this study what Maguire, Quint, and others had also observed, namely that as many as one-third of the cancer patients felt that they had received inadequate information about their diagnosis. This group of authors concluded their report with the suggestion that intervention might be appropriate at an early stage for those patients likely to be at risk, identified through psychological testing.

Curable carcinoma of the rectum and sigmoid colon, with resultant abdominal-perineal resection and permanent colostomy can also result in serious long-term adjustment problems, depending upon colostomy function, personality organization, and felt significant-other support. Rowbothom, (13) speaking of his experience in a colostomy clinic, pointed out that colostomies frequently impose long-term problems despite a 'myth' that time alone results in resolution. These problems are dependent on the distance of the stomal opening from the ileosecal valve, and the status of general health of the individual. There may well be intermittent discharge of feces, of fluid, and of gas and mucus. Changing the diet to a low-roughage meal may not help much, and irrigation does not always work to eliminate the difficulties. Odor can be a real and on-going problem. These dysfunctions need continual re-assessment and professional guidance. Underlying depression is not uncommon in many patients and can interfere with social adjustment. Bronner-Huszar (14) has observed that in the compulsively clean personality, colostomy can engender feelings of self-hate and self-disgust, as well as phobic responses such as obsessive-compulsive cleansing that can keep a person tied to a toilet for hours at a

time. Marital problems are not rare; sexual impotence may be aggravated in the male (variable neurological damage may occur surgically, interfering with erection capacity). Loss of male potency has been stated to occur in a range of 20-90% of cases, with a greater incidence in the elderly male. For women, the sense of being sexually acceptable is frequently injured. For both sexes, fears related to the stoma become aggravated when intimacy with another is considered. Concerns of rejection by the partner frequently causes retreat from this exquisite area of human pleasure. Actual rejection by the sexual partner has been noted due to the partner's own problems with body image and with wounds; such rejection can result in long-term psychological disability, with aggravated self-hate, and diminished feelings of self-esteem, and a resultant loss of zest for life.

Druss, in 1969, observed that depression, accompanied by libidinal reduction, was common after colostomy (15). Dlin and Fischer, (16), in a recent report on colostomies, quoted a European study of Basler, in which 110 patients with rectal cancer were followed for up to 14 years. While 77% of these patients indicated that they had made an eventual complete acceptance of their colostomies, virtually all the patients reported that they needed a year or more for adaptation to occur, during which time at least 60% of them had experienced depression, feelings of being an invalid, and a feeling of limited acceptance by their spouses, friends, and fellow employees. In general, they also developed a reduction in their working capacity. Over the course of the year, about 38% of this group had to be readmitted to the hospital because of problems in colostomy adjustment. Mourning for the lost anus, the process of which explains some of the above complaints, lingered for a year or longer, and acceptance of the new body image depended upon the completion of successful mourning. As noted, 23% of Basler's patients never quite succeeded in completing this task.

Dlin commented further that where family, or social relationships, were characterized by tension, hostility or lack of care, delay in self-image recovery could be expected.

Other aspects of personhood, apart from relationship to the body, also plays an enormous role in the definition of self-esteem. In addition, an individual's self-esteem is also determined by symbolic and functional definitions that are explicitly and implicitly taught in his culture. For example, to feel a sense of independence in day-by-day functioning, to feel in control of one's self and of events impinging upon the self, and to feel secure and invulnerable rather than helpless and breaking-down, are all integers of mental health in the United States. The diagnosis of cancer threatens these reference points. One such additional reference is a perspective of the future. Having a future seems critical for secure mental functioning for most people.

Shands (17), in 1966, described as one of the major psychological reactions to the diagnosis of cancer, a loss of orientation for the future, a feeling of a 'sudden amputation of the future'. This explosive realization inherent in a fatalistic implication of cancer, brings about a futurelessness, and has been described as akin to 'a blow on the head', a shocking impact. In a somewhat hyperbolic tone, Brennan (18) argued that 'in an industrial,

technological society which perforce expends most of its efforts in the construction of future benefits and accomplishments, and characteristically places its hopes of achievement, order and happiness in the future, to provide escapes from the present, not to have a potentially triumphant future which one can share with others, for all practical purposes, is not to exist in the present either'. Cancer in this sense is sudden confrontation with life's limits, and for many, such confrontation is deeply terrifying. Brennan's implication is that futurelessness becomes a perspective of the cancer patient, and that this perspective is shared by the family and by society at large. Such a perspective disenfranchises the cancer patient, both as he sees himself, and as others view him. Thus, continued Brennan, the cancer patient can best be understood as a victim of deprivation and isolation rather than of fear, anguish or grief. But there really is little need to place the cancer patient in an either-or position. The fear, anguish and grief are real enough; feeling isolated and deprived is easily interwoven into the patient's, and indeed the family's, gestalt.

Cancer is frequently associated with feelings of guilt and shame. Guilt is the expression that the disease is somehow the patient's own fault for an act of ommission or commission, or for not resisting an assault upon him by some other person. Abrams and Finesinger, (19), in 1953, explored in-depth these guilt reactions, and hypothesized that in order to find meaning in an otherwise chaotic occurrence, people explained their disease as their specific, self-created vulnerability. Guilt projected on to another becomes blame, and as Shands, et al, (20) pointed out in 1960, blaming another for being the outside agency that brought disaster to the patient is not at all uncommon. However, blame can easily lead to the alienation of a needed other, creating rifts and gulfs in human relations when they are often most needed. Shame not infrequently accompanies guilt, and appears to be the publicly oriented sensation of having been singled-out for an uninvited disaster, or for letting others down in a manner which threatens the role-relationship and the worth of one person to another. The present day frequency of these psychological responses to the diagnosis of cancer, the longevity of such responses, and the interfering capacity for social adjustment, has not been given statistical examination. But there is little reason to doubt that human beings respond today as they did a few decades back, and that these psychological factors interfere with human adaptation.

Tensions and problems related to dependency feelings were pointed out by Sutherland some years ago (21). Cancer is a disease which breeds great helplessness. The patient and the family often feel a sense of incompetence to manage problems associated with the illness. A complete dependency on the medical system frequently emerges, and can lead to conflicts over dependency problems from the past, especially in a society that places great stress on independence. Not infrequently, depression and hypochondriasis result, although again, statistical frequencies have not been reported in the literature. Helplessness is accentuated as long as sickness, or treatments, lasts. A person is apt to feel less helpless when returned to normal living. However, lingering pessimism regarding the future, and one's worthiness, can cause defeatism and helplessness. Such sensations obviously interfere with a person's re-entry into the world of the active living.

Psychological terms are far from standardized, and depending on the outlook and frame of reference of the author, differing descriptions of human psychological invalidism, or strength, are depicted. In a recent attempt to quantify the frequency of various adaptational problems (the term adaptational is employed in this sense to depict a psychological manner of coping with stress) besetting the patient in the early days of the cancer diagnosis, Weisman and Worden (22) obtained information from 120 patients with a variety of cancer diagnoses, rather than just breast or bowel cancer, who were willing to participate in the study during a period of 100 days after the diagnosis was made. The authors pointed out that the level of 'disturbance' was mild for some, and quite significant for others. Patients falling into the category of greater emotional distress were found to have the following characteristics: a) had many regrets about their past lives; b) were generally pessimistic about their outcomes; c) had experienced marital difficulties; d) came from a multiproblemed family; e) were widowed or divorced; f) expected little or no support from significant others. These 'high emotional distress' patients were also found to be passive folk who supprssed worries, withdrew from active participation in decision-making, and then submitted rather fatalistically to treatment. On the other hand, patients who appeared to have low levels of emotional distress tended to accept their diagnosis, talked openly with professionals and others in order to clarify their misgivings or questions about treatment, kept an open time perspective, and felt generally optimistic. The authors pointed out, however, that for all patients, the longer that they were kept in therapy radiation or chemotherapy, the more threatened they felt. The more rapidly the patients returned to a normal life, the more rapidly the threatening visage of cancer diminished. In some ways, the Weisman and Worden data are in concert with that of Morris, et al. Whereas the latter employed psychometric testing to describe pre-operative depression, and high levels of neuroticism in certain breast cancer patients who are vulnerable to long-standing upsets, the former avoid such descriptions, but used an attitude-to-life-experiences type of evaluation to come to the same conclusion. Perhaps the two descriptions are matrixed. At any rate, spotting people who are apt to be in adaptive trouble does seem possible, even early in their cancer career.

Most importantly, Weisman and Worden pointed out that a patient could be deeply disturbed without overt signs showing. Interviewing skills were required before candid information emerged. This latter point is most significant, since there are several published surveys that report on the cancer patient's long term adaptation, in which little psychological or social deficit is revealed. The latter information, however, was gathered mostly by a mail return questionnaire, without interviewing the respondents. (The data on the breast cancer patients reported earlier in this paper were collected directly from patients at home.)

The matter of felt support, from both the physician and the family, especially the spouse or sexual partner, is alluded to in a number of studies. Feder made the point that the medical staff in a radiotherapy clinic generally avoid close contact with the patients, and do not explore the patient's reactions to the illness nor to the therapy (23). Quint, in the work mentioned prior, wrote in her concluding comments...'living with this new identity (cancer) and facing the possibility of a painful and difficult way of dying, is not an easy

task, and is often a lonely one, because laymen and professional people alike withdraw from interactions which stimulate personal identification with the problem'. Patients with cancer, according to Quint, may be judged by themselves, and by others, to have a stigma which leads to isolation from others. Brennan's comments about 'deprivation' are most pertinent here. These feelings are worsened if there is a delay in healing or a problem with a prothesis.

Quint further pointed out that the patients she interviewed felt strongly that encounters with the physician and nurses were critical for them. Yet most patients felt that they were poorly informed by staff as to what was happening, or what to really expect. Surgeons would allow patients to take the initiative in asking for details, but the patient did not often do so. Thus few details were specifically offered. Family members, especially spouses, were often given a different set of details regarding diagnosis and treatment expectations. Husbands, however, were not counseled as to what to say, and often did not know what to communicate to their wives. Thus, frequently, blocked or confusing and irritating language was employed, and patients found themselves uncomfortably angry and confused for many months after the surgical procedures. Quint quotes one patient, seven months post-operative, who felt ..'very nervous, very irritable...I'm a changed person'. And in talking about her husband,...'I've a terrible hatred. I'm crying a lot. Can't tell you why I do. He can just look at me and I'll bawl...my nerves, let down...everything irritates me. He irritates me. I just want to do something to shut him up, or to have him leave me alone.'

Maguire, whose work in England was alluded to before, also discussed communication and affect problems in the post-mastectomy women. He pointed out that the women were reluctant to share their emotional and social problems with the medical and nursing staffs (nor,indeed, with their spouses), even when given an obvious chance to do so. There was a general reluctance on the part of physicians to probe into their patients' lives, or affects, for fear of upsetting them. The surgeons themselves avoided conversation when they felt inadequate, or helpless, to do anything about what might be revealed. These doctors did not pick up on clues, or even overt statements, dropped by their patients. Maguire suggested that another explanation for the avoidance techniques of the physicians was related to the doctor's needs to maintain his own emotional equilibrium. To get too close to the pain of his patients might throw him off balance.

Maguire further indicated that inconsistent communications between the physician, the patient, and the family caused significant, long-term turmoil for the patient. The changing of therapeutic decisions, inconsistent information from day to day, differing statements of medical information by different members of the medical team, and inconsistent communications to different members of the family all resulted in frequent long-term havoc for the patients involved.

Morris, et al, make the same point: namely that one-third of the cancer patients that they interviewed felt that they had received inadequate information about their diagnosis.

There is not too much detailed information available regarding the personality characteristics, the illness reactions, and the behaviors of 'significant others' in relation to the adaptational requirements of the patient. Commentators all seem to agree that felt support of the other is critical. The anecdotes of Bard, Quint, and others indicate that 'significant others' undergo a range of responses, from full and loving support, to such reactions as guilt (strong men do not let such things happen to their wives), or to phobic reactions to the scar, with subsequent avoidance reactions. In some situations, spouses have been known to infantilize patients by taking over all their adult roles; this excessive 'protection' has been not infrequently noted, and patients have complained bitterly about being treated like a sick and helpless person. Such compensatory reaction can result in anger and hostility by a patient who would prefer not to be reminded continuously that they are now less of a person. Since the significant other is not routinely interviewed and 'diagnosed' as part of the medical work-up of a potential or actual cancer patient, systematic data is non-existent, and therefore any attempt to develop more than a cursory picture of the adaptational problems of patient, in regard to the felt need of the other, is premature. Nevertheless, in broad terms, it is probably safe to say that difficulties in a marriage relationship before cancer are frequently aggravated once the disease appears, and that the diagnosis places new strains and stresses on a marriage, especially where communication is blocked, or distorted.

Body-image problems are obviously lessened when an internal cancer is diagnosed, such as cancer of the lung, or the pancreas. However, an absence of 'disfigurement', either by the disease, or by treatment, does not alter many psychological consequences. Hidden cancer provokes its own set of turbulences, since the patient and family can never be sure of what's going on inside when there are no visible landmarks to go by. Deeply disturbing feelings of 'being eaten-up alive on the inside' may develop, and usually kept secret from discussion with others. Any ache or pain may be disturbingly interpreted as a recurrence, and glib reassurance may not give much peace. Patients may become functionless, hopeless, despairing just as easily as may an individual with a 'surface' cancer. Depending on the personality organization, sense of security, and openness of communication, a person with any cancer gets on with life, or gets bogged down.

RECOMMENDATIONS

A). A key element in bringing about change in both the appreciation of, and improvement in, adaptational problems for the cancer patient rests in education of the health professionals who are involved in their care. These involve medical students, house officers, practicing physicians, nurses, social workers, and others. As a first step in an educational effort, there must be an elaboration of a biopsycho-social model of disease, as opposed to a rigid, biological definition of cancer. As Engel has recently postulated (24), the biological model, successful as it has been in so many instances, is grossly insufficient to either explain, or to modify, the impact of serious illness on human suffering. Without a full understanding of the impact of cancer and its therapy on human adaptation, the physician, as well as the other professionals mentioned, will tend to concentrate only on the biological and the technical

aspects of disease. Clearly, a better understanding of disease as a patho-physiological process, and continued improvement in the technologies applied to the management of cancer, will lighten the psychological burdens inflicted upon patients. Were amputative surgery not required, or simpler anatomical destructive procedures available, the mutilative feature of cancer would be lessened.

Not paying attention to the psychological and social burdens that accompany the disease places the patient in a potentially handicapped position for an indefinite period of time. The medical schools, their teaching hospitals, as well as continuing medical education programs in the community hospitals of the nation, need to be encouraged to place approriate accent upon psychosocial elements of illness, especially as these elements function to debilitate the individual in an out of-the-hospital setting. This will not be necessarily an easy program to implement, as attractive as the abstract idea may be. As Wood has recently pointed out (25), medicine's responsibility for complex social, psychological, marital, and human adjustment problems has grown considerably in the past several decades, probably in response to the erosion of the complex social organization that 'solved' such problems within its existing framework in the past. This relatively new responsibility of medicine has not been acknowledged universally by medical personnel, especially physicians, and considerable confusion, as well as resistance against becoming 'involved', still exists. In such a setting, an adversarial position is apt to evolve between those who insist that more involvement with human suffering is necessary, and those who see themselves already fully employed attending to the medical and technical needs of the hospitalized patient. Such divisive argument should clearly be avoided in any educational programming. Yet, it is not difficult to foresee that a continued resistance to taking on psychosocial responsibility will continue, as will resistance to allowing psychologically trained others to have a 'piece of the action'. Education is therefore conceived as a slowly moving device to restructure thinking in this area of concern.

B). Secondly, it is important that the biases, attitudes, and values of medical personnel be explored in a self-reflective, non-judgmental manner. An understanding of the patient's needs and the capacity to be available to inquire, understand, and act accordingly, is relative to the physician's (nurse's) attitudes, prejudices, and their own personal needs. Physicians who are overly self-protective will not be available for their patient's psychological wounds. Such medical personnel tend to appear authoritarian or distant in their approach to patients, and are apt to act overly pessimistic, or optimistic, in regard to their own internal psychological make-up. But in such a mode, they are clearly out of step with their patients' requirements. Physicians who feel vulnerable, threatened, insecure, or frightened will often go to extremes to protect themselves, and find difficulty in allowing another to be supportive of them. The right setting for such explanation is needed. Artiss and Levine (26) described a seminar-setting for physicians in training in which, through a case presentation, a liaison psychiatrist attempted to help the staff examine their own feelings in regard to issues in management and interaction with oncology (cancer) patients. As the authors point out, it takes patience, endurance and tolerance to get a conference of this nature to continue in an ongoing fashion, since physicians tend to view, initially, the meetings as a

waste-of-time (really meaning, threatening). Nevertheless, some good did emerge after the physicians began to 'trust' the group leader and each other. and could begin to explore their guilt, their frustrations, and their anxiety. Seminars of this kind should be encouraged as part of the training of physicians who will spend a considerable amount of their professional time caring for cancer patients. Certainly, this sort of training should become a vital aspect of medical oncology, radiation oncology, and surgical oncology training programs,as well as elements in the training of multi-disciplinary professionals e.g. (nurses, social workers, pastoral counselors, etc.). While harder to visualize, seminar elements of this kind need to be created in community hospitals for professionals, for it is in the community hospital that the vast majority of cancer patients receive their primary care.

C). Physicians, and others on the medical staff, need more training in simple psychotherapeutic techniques, in order to feel a sense of competence in allowing and, in fact, encouraging a patient's concerns and feelings to emerge. With some training in this sphere, a physician may feel more comfortable in being supportive to patients, as well as to the concerns of family members and to other staff members. The majority of patients do not need psychiatric assistance, as much as they require an empathic physician who can understand and be available to their needs for direct and open communication, ventilation of feelings, and exploration of shattered self-esteem that comes about as a result of the diagnosis of cancer and subsequent treatments.

D). But in addition, there is a pressing need to develop the special staff of individuals, associated with cancer centers and with community hospitals, whose purpose would be to initiate a psychosocial evaluation of all new cancer patients and their families in order to recognize those individuals who are highly vulnerable to psychological and social upheaval as a result of a cancer diagnosis and treatment. There is some evidence that cancer centers are already utilizing such personnel to some extent, but there is a great dearth of such personnel in the community settings. Such staff should also be employed to follow patients after discharge (and their families) in the community for at least a year in specified situations. The vital question of financial support for such professionals is of immediate concern, as is the acceptance of such efforts by the physician involved. Third party payment for such efforts does not exist at the present, and it would probably take considerable effort to convince various third party payment insurance agencies of the merit of such professional activity. Qualified professional personnel, such as social workers, psychologists, pastoral counselors, do not qualify for third party support under most circumstances. The financial pressures on American medicine is already enormous, and to create another expensive service cannot be suggested cavalierly. Figures do not exist as to the actual time and money lost to the commercial sector of the nation in the wake of psychosocial disorders secondary to cancer, and thus no argument could now be launched to imply that services of the type alluded to would, in the long run, save money. Nor could proof be offered at this time that third party payment for such services would automatically improve the mental health of all cancer patients, or even a significant segment of them. Nevertheless, evidence to

date seems convincing that suffering, on a long term basis, does occur for a significant number of otherwise curable cancer patients, and that their adaption back into worthy and useful full life is hampered by the impact of cancer.

E). Bard concluded his paper on the Price for Survival of the Cancer Victim with the comment that, 'many lives saved by medical technology are doomed by psychological invalidism. Sound psychological preparation during early illness and hospitalization could minimize this trauma.' But he offered no specific therapeutic program. Many have appeared in this country,launched in efforts to bring relief to the isolation, despair, pessimism and debilitation of the cancer patient.

These therapeutic programs include patient education groups, professionally-run patient and family support groups, patient-to-patient support groups, etc. These interventional attempts, at present, reach relatively few patients and families, even though several reports indicate that certain centers have become rather proficient at offering these opportunities. There has been relatively little evaluation performed as to the effectiveness of the various interventions in terms of specifically stated goals. Criteria are needed to critically judge what is being effected, and what the goals of the various interventions are. There is also a need to evaluate the exportability of such programs from the urban centers, where in general they have been initiated, to other community settings where significant numbers of cancer patients both reside and receive their initial therapy.

One patient-to-patient support group is the Reach to Recovery Program initiated over a decade ago. Many anecdotal tales abound about the courage of these mastectomy visitors, and the help they offer to the newly operated-upon patients. However, there is little documentation of the long-term adaptive value of the program. In most States, this volunteer program can be implemented only through a surgeon's request, and I was recently informed by the Massachusetts American Cancer Society that only 38% of operated women in this state, received a program visitor in 1977, according to a recent study evaluating the impact of Reach to Recovery in the Boston area (27). Approximately 90 women, ages 29 to 82 years were divided into 3 groups at the time of their initial surgery (radical, or modified radical, mastectomy). One group served as a control, receiving no program visitors. A second group was visited in standard fashion by the area Reach to Recovery Volunteer. The third group was visited by a person especially trained in interpersonal communication skills. Ms. Linda Brown (author of the study) visited each patient at home, 1-3 months post-surgery, and found that while in retrospect the mastectomy patients felt that all visitors, volunteer or trained, were valuable, the group that received the specially trained visitor seemed to be functioning better, as manifested by less overt expressions of anger, less tranquilizer usage, and less alcohol usage. This study as part of Ms. Brown's doctoral dissertation, will be published shortly.

Ms. Brown concluded from her study that overall, about one-third of these women were depressed both publicly and privately. A third were functioning publicly, but depressed privately, and a third were functioning well

privately and publicly. Ms. Brown felt that at least 2/3 of this group of patients needed ongoing support that they were not receiving, although she could not predict for what length of time help would be needed.

Further evaluation as to the effectiveness of organizations such as Reach to Recovery is needed, especially in comparison to a trained cadre of helpers. Should the latter prove more 'effective' in assisting patients adapt to the impact of cancer, than the need to either 'train' selected volunteers in interpersonal skills, or in fact, employing trained professionals, would become apparent.

An example of a patient support group mainly, but not exclusively hospital based, is the CanSurmount Program in Denver. This program is directed by a young woman who had cancer several years back. CanSurmount is a group of patients and their families, who meet to discuss affects, communication-barriers, family adaptation, etc. New patient visits are included in their activities. From personal observations, I would judge that both the patients and their families receive good support from the group, and function 'better' in society because of this self-support. Groups of this nature tend to run on a volunteer basis, with little external financial support. Such groups also need vigorous leadership to become established and to continue functioning.

Professionally led groups have sprung up around the country, typified by a program at the Mt. Zion Hospital in San Francisco. Several patient groups were formed at that institution, supported originally by Federal funds. A group of young adult patients was formed, as was an older patient group, and a family group. The groups were led by a trained social worker, or psychologist, with back-up support of a psychiatrist. The family group has apparently fizzled (verbal report by Dr. N. Mages), but the two patient groups continue even with termination of Federal support, support now for the involved professionals coming from the hospital. An evaluation of the program is underway.

Wellisch reported upon the activity of a multiple-family therapy group in Los Angeles. Directed by a clinical psychologist, the first 7 months of the program was for family members only. These individuals often expressed rage, sadness, fear of recurrence, and guilt. When the patients also began to attend, the effectiveness of the program in opening intra-familial communications seemed to improve, and the life functions of patients and families seemed also to improve (28).

Yet, it would seem that the majority of patients today do not have access to such groups. Despite an absence of systematic verification of efficacy, it would appear that groups offer an element of therapeutic potential that need greater examination and evaluation.

F). Continued evaluation of reconstructive mammoplasty, and other reconstructive operative procedures, are indicated. There seems to be little doubt of the psychological value of reconstructive procedures for the facial areas when they are involved. There seems to be quite a bit of uncertainty as to the value of mammoplasty. At the recent American Cancer Society Conference on Human Values, held in Chicago in the fall of 1977, Francine Timothy made a

stirring plea, based upon her study of several hundred mastectomy patients of all ages, regarding the value of the procedure. She emphasized that the importance of reconstructive surgery was generally misunderstood by most general surgeons, who felt that the patient, especially the older woman, should be satisfied that her life had been saved by the amputative manuever. Reconstructive mammoplasty is seen as vanity, and physicians may deride patients for this sentiment. Timothy argued as to the crucial issue that this 'vanity' implied women could be embarrassed into silence in the presence of their physicians, and allow themselves to be cowered by implications of their feminine 'silliness'. Certainly, if the procedure offers an opportunity of improved adaptation to mastectomy, on-going evaluation is needed. Identification of the patient most apt to benefit, the impact of the procedure on recurrent disease, and on the physician's ability to recognize early recurrence, are all important issues.

G). Further research into identifying, early in the career of the patient with cancer, those characteristics of personhood that are associated with either adaptive,or maladaptive, short- and long-range outcomes is necessary. The development of simple psychometric, or life-events, predictive scales which can be universally employed, are needed. Work-up of patients in a hospital when the diagnosis of cancer is being entertained, or had been established, along psychological and social evaluation has been performed. Similar to a pap smear, or a chest film, such psychosocial evaluation should serve as a signal that the patient is in trouble, and needs treatment. While the search continues for the best mode, or modes, of patient and family treatments, evaluation of diagnostic methods are also urgently needed. If the physician, or nurse, had an 'easy' diagnostic procedure, one that did not encompass other specialists, or excessive time, the enthusiasm for psychosocial evaluation and treatment should rise considerably.

H). Further characterization of the psychological wounds experienced by family members when an individual develops cancer, and undergoes significant alteration of body image, is needed, especially in light of the crucial role that the significant other, or others, play in the adaptation of the patient. Little had been done to evaluate such phenomena, not to evaluate support roles and interventions for family members. While some mention is made in the literature as to the impact on spouses, the effect on the developmental lives of children have received relatively little attention. This is an area of potentially significant mental disturbance that needs clarification.

REFERENCES

1. Bard, M. The Price of Survival for Cancer Victims, in Where Medicine Fails. ed. Strauss, A. Aline Press, 1970, pp.99-110

2. Tarlan, M. and Smalheiser, I. Personality Patterns in Patients with Malignant Tumors of the Breast and Cervix. Psychosom. Med. 13:117-121, 1951

3. Bacon, C. L., Renneker, R., and Cutler, M. Psychosomatic Survey of Cancer of the Breast. Psychosom. Med. 14:453-460, 1952

4. LeShan, L. L. and Worthington, R. E. Some Recurrent Life History Patterns Observed in Patients with Malignant Disease. J. Nerv. Ment. Dis. 124:460-465, 1956

5. Bahnson, C. B. Psychophysiological Complementarity in Malignancies: Past Work and Future Vistas. Ann. N.Y. Acad. Sci. 164:319-333, 1969

6. Bard, M. Psychological Impact of Cancer and its Treatment. IV. Adaptation to Radical Mastectomy. Cancer 8:656-672, 1955

7. Ervin, C. J. Psychological Adjustment to Mastectomy. Medical Aspects of Human Sexuality. 7:42-65, 1973

8. Quint, J. Mastectomy-Symbol of Cure or Warning Sign. G. P. 29:119-124, 1964

9. Maguire, P. The Psychological and Social Sequelae of Mastectomy, in Modern Perspectives in the Psychiatric Aspects of Surgery ed. J. Howells, Bruner/Mazels 1976

10. Jamison, K. Rl, Wellisch, D. K. and Pasnau, R. O., Psychological Aspects of Mastectomy I. The Soman's Perspective. Amer. J. Psychiatry 135:432-436, 1978

11. Asken, M. J. Psychoemotional Aspects of Mastectomy: A Review of Recent Literature. Amer. J. Psychiatry 132:56-59, 1975

12. Norris, T., Greer, S., and White, P. Psychological and Social Adjustment to Mastectomy. Cancer. 40:2381-2387, 1977

13. Rowbotham, J. L. Colostomy Problems-Dietary and Colostomy Management. Cancer. 28:219-238, 1971

14. Bronner-Huszar, J. The Psychological Aspects of Cancer in Man. Psychosomatics. 12:133-138, 1971

15. Druss, R. G., O'Connor, J. F. and Stern, L. O., Psychological Response to Colectomy II. Adjustment to Permanent Colostomy, Arch. Gen. Psychiatry. 20:419-427, 1969

16. Dlin, B. and Fischer, H. K. Psychiatric Aspects of Colostomy and Ileostomy in Modern Perspectives in the Psychiatric Aspects of Surgery. ed. J. Howells. Bruner/Mazels New York 1976

17. Shands, H. C. The Information Impact on Cancer in the Structure of the Human Personality. Ann. N.Y. Acad. Sci. 159:883-889, 1966

18. Brennan, M. J. The Cancer Gestalt. Geriatrics. 96:101, 1970

19. Abrams, R., and Fiensinger, J. F. Guilt Reactions in Patients with Cancer. Cancer. 6:474-482, 1963

20. Shands, H. C., Fiensinger, J. F., Cobb, S., and Abrams, R. Psychological Mechanisms in Patients with Cancer. Cancer. 4:1159-1170, 1960

21. Sutherland, A. M. Psychological Impact of Cancer and Its Therapy. Med. Clin. N. Am. 40:705-720, 1956

22. Weisman, A. and Worden, W. The Existential Plight in Cancer: Significance of the First Hundred Days. Int. J. Psychiatry in Med. 7:1-15, 1976

23. Feder, S. L. Psychological Considerations in the Care of the Cancer Patient. Ann. N.Y. Acad. Sci. 125:1020-1027, 1966

24. Engel, G. L. The Need for a New Medical Model: A Challenge for Biomedicine. Science. 196:129-136, 1977

25. Rogers, D. E., and Blendon, R. J. The Academic Medical Center: A Stressed American Institution. NEJM 298:940-950, 1978

26. Artiss, K. L., and Levine, A. S. Doctor-Patient Relation in Severe Illness. A Seminar for Oncology Fellows. NEJM 288:1210-1214, 1973

27. Brown, Linda Needs of Mastectomy Patients-An Intervention Study-Doctoral Thesis-(Personal Communication) to be published.

28. Wellisch, D. K. Helping Families to Cope. Internal Medicine News, 1 Aug. 76

SUMMARY OF IMPLICATIONS FOR CANCER REHABILITATION

SERVICE DELIVERY NEEDS

There is a special need to incorporate early psychosocial evaluation of all cancer patients and their families in the routine cancer treatment process.

There is a need to support not only the efforts of volunteer groups but further study of such groups to learn the ways in which they are effective and for which populations they are most effective.

There is a need for the vocational rehabilitation system to reassess the medical criteria used as a basis for decisions on acceptance versus rejection of cancer patients for vocational rehabilitation services.

There is a need for patients and family to be recognized as having full rights in the partnership with the professionals who are involved in therapeutic and cancer rehabilitation efforts.

PROGRAM AND POLICY DEVELOPMENT NEEDS

There is a need for the education of health professionals in understanding the biosocial model of disease as well as the current biological model. This should include emphasis on both the psychological elements of illness and the complex interaction between physical variables involved in the total healing process. To seek to achieve physical restoration alone, without responsible effort toward psychosocial restoration is counterproductive and may not be possible.

There is a need for seminars for physicians so that their own biases, prejudices and attitudes can be explored in a non-threatening manner. The purpose of such seminars would be to overcome the authoritarian or distant approaches of some physicians which are either overly pessimistic or optimistic and are guided by subjective psychological biases.

Community hospitals should become the focus for educational seminars of a multispecialty, inter-disciplinary nature, since that is where eighty per cent of cancer patients are first diagnosed and receive their earliest primary care.

There is a need for physicians to receive additional, more focused training in simple psychotherapeutic techniques specific to the supportive management of the cancer patient and those who care for cancer patients.

There is a need for therapeutic programs to be expanded to include patient education groups, professionally directed family and patient support groups, patient to patient support groups and other voluntary community support efforts.

There is a need to educate those individuals within the support environment regarding knowledge of cancer as a disease, treatment, as a curative process and the meaning of both for living.

There is a need to compensate for (1) the lack of current information on the care and treatment of cancer on the part of those engaged in vocational rehabilitation, (2) the lack of aggressive and consistent education programs directed toward the health care and rehabilitation profession on the rehabilitation potential of persons whose cancer has been cured or controlled and (3) the lack of consideration of rehabilitation and vocational goals early in the treatment planning for the individual cancer patient.

There is a need for the development of "program cooperatives" involving community-wide participation and employer involvement which are designed to return cancer patients to the main stream of economic life in America.

There is a need for vocational rehabilitation agencies to establish affirmative action programs designed to facilitate the entry of cancer patients into the rehabilitation process and to provide incentives for physicians and counselors to consider and work with the rehabilitation needs of these patients.

There is a need for professional seminars dealing with the ramifications of cancer and employment and these seminars should be directed toward industrial physician, social workers, vocational counselors and occupational nurses.

There is a need for expanded involvement of labor and management in cancer rehabilitation in order to facilitate a significant reduction in the apparent stigma of cancer which creates barriers to employment. Access routes to be utilized should include large, individual corporations, trade associations, employer associations, personnel management groups, chambers of commerce and service clubs.

There is a need for affirmative action to stimulate the application of the directives of the Vocational Rehabilitation Act of 1973, and especially Sections 503 and 504.

There is a need for concerted effort to influence the American College of Surgeons and the American Society for Clinical Oncologists to add rehabilitation issues to their standards for cancer treatment, with emphasis on interdisciplinary involvement.

There is a need for concerted effort to establish the policy that psychosocial descriptor be included in Tumor Registry Information.

LEGISLATIVE NEEDS

There is a need for provision of third party payment for the services of professional personnel, e.g., social workers, psychologists and vocational counselors which are necessary for the accomplishment of the goals of cancer rehabilitation.

There is a need for future legislation to include provisions for independent living, recognition of cancer as a catastrophic illness and for full provision for funding of rehabilitation services as an integral part for the cancer rehabilitation.

There is a need for the establishment of a rehabilitation research and training center for cancer rehabilitation or of a core area for cancer rehabilitation in existing research and training centers.

RESEARCH NEEDS

There is a need for investigation of how many dollars are lost to the commercial sector because of psychosocial disorders which result from the diagnosis and treatment of cancer.

There is a need for the rigorous evaluation of the effectiveness of various psychosocial interventions in the area of cancer rehabilitation.

There is a need for the continued evaluation of reconstructive mammoplasty and other reconstructive procedures, including consideration of their psychosocial ramifications and the availability of third party payments.

There is a need for research to identify the characteristics of these persons that are predictive of adaptive or maladaptive, short- and long-range outcome, in order to establish treatment goals for the individual patient.

There is a need for special study of the impact of cancer on family members and especially of the impact of cancer on the developmental and functional lives of children.

There is a need for the establishment of minimum standards of cancer rehabilitation employing a systems approach to the conceptualization of the planning, implementation and evaluation processes.

There is a need for the development and use of objective measures of effective performance in real jobs and real life situations, based upon abilities.

CHAPTER 3

EPILEPSY: ACTION FOR REDUCING BARRIERS TO EMPLOYMENT AND COMMUNITY PARTICIPATION

Author: Betty S. Hedgeman, Ph.D.

"The paper provides essential insight into the needs of the person with epilepsy. I fully agree that service delivery needs must include medical, psychological, vocational, public education and information, housing and transportation and advocacy. Implied from the discussion is the necessity for the vocational rehabilitation program to become more involved in public (includes employers) education and advocacy.

Of great importance is the need for Rehabilitation Counselors to become better informed about epilepsy; to avoid stereotyping clients with epilepsy into a narrow span of occupations; to better inform employers about the person with epilepsy, as well as Sections 503 and 504 of the Rehabilitation Act of 1973.

I disagree, however, with the author's proposal to change the financial support system, wherein the person with epilepsy would be given money directly rather than receive it from programs. Why not then give money directly to a person with any disability? I can perceive such a practice getting out of control.

Additionally, I believe that programs can provide considerable assistance, e.g., vocational guidance counseling and advocacy which would not otherwise be available.

In conclusion, I would indicate agreement with the author's final recommendations. We do need a comprehensive educational effort to overcome the ignorance and barriers now being faced by those with epilepsy. To accomplish this will require additional funds, legislation, research and advocacy."

Excerpts from comments by Morris C. Hansen, C.R.C.

INTRODUCTION

Epilepsy has affected society throughout the ages and to this day, there is relatively little acceptance of the fact that this neurological disorder can cause the psychosocial and vocational problems which prohibit people from functioning effectively in society.

As is usually true, society tends to deal with problems in as academic or scientific manner as possible. What this has meant for persons diagnosed

as having the condition known as epilepsy is, that they have been medically treated and, in some instances, studied. Rarely has that acceptance or the action needed to have them function effectively been present, nor has it been developed.

For the purposes of this paper, by eliminating from consideration the person with epilepsy who has additional developmental disabilities, still over a million persons are considered. In this society those persons continue to be stigmatized by having a condition for which they must feel guilty and responsible. It is the belief of most of the public that it is still the person's fault for having a seizure. Even those who are more knowledgeable, attribute seizures solely to the factor that insufficient medication was taken. Society has made the taking of pills into a magical solution to prevent disabling conditions from occurring. For the person with epilepsy who has usually completed medical evaluation through a long and complicated process, it is suggested that the seizures experienced might be controlled by taking a combination of pills. To those persons who have the benefit of understanding families; the good fortune of being placed in communities where there is acceptance; by attending schools where this is not a problem; and by finding employment where seizures occurring do not adversely affect their state of employment; all is well and good. Unfortunately, what usually happens is that the taking of those pills makes the individual different. If this particular problem occurs during adolescence or young adulthood when acceptance and 'being normal' are so central to the young person's psychological and social development, it becomes an even worse problem. Having epilepsy does not make you look any different from any other person. Also, you breath the same, eat the same, and have the same desires psychologically, vocationally, socially, sexually, emotionally, and otherwise. Yet, society has labeled as different the person who has that brief episodic event which takes perhaps a few seconds or minutes out of the total seconds or minutes of the day. For most persons this event may not even occur daily, but they are labeled for their disability and not their capabilities or other positive attributes.

Any difference in any person is cause for rejection and this rejection includes the most important areas of employment and the ability of participating in the community to one's fullest expectations. Both of these essential ingredients of employment and community participation are critical to one's life on the basis of the moral-religious ethics which have been instilled in society for most of its existence, as well as the right of each individual to achieve self-actualization.

This is the very process that has put the person with epilepsy in conflict with the rest of society, thus creating barriers to employment and community participation. The person appears to be the same as everyone else, yet that invisible or hidden quality which manifests itself in the form of a seizure creates the difference which causes the rejection resulting in those stated barriers.

PROBLEM

Epilepsy is not primarily a medical problem in the context of this paper since the medical aspects, for the most part, are being addressed. Money has always been assigned for that scientific research that makes society feel it is adequately attacking the problems of its disabled population. What society does not deal with are problems which involve its own members. While these problems include various psychosocial aspects, the one problem that is most important for society's attention is acceptance of the person and that person's right to employment and community participation. This does not mean the person should be relegated to a special section of town; special building; or an institution. The person does not need a special agency to care for needs; a special recreation program; a special workshop; or any other device that will prevent optimal functioning in the mainstream of society. Obviously to accomplish those goals, it will be necessary for society to change and it is sometimes necessary to assist society in making those changes. In the case of epilepsy rehabilitation, that change might best be assisted by the following mechanisms:

A. Service Delivery: The areas of service delivery most needed for this population are the same areas that most persons (without seizure disorders) would need in order to function effectively in society.

1. While it has been stated that a medical problem does not exist, that statement is essentially true as long as the individual with epilepsy continues to take the medication and attends to the appropriate medical treatment as prescribed by a competently trained practitioner in neurology, preferably one specializing in problems of epilepsy. Accurate diagnosis and treatment is essential to maximum functioning. It is also imperative that this medical cost be established at a level that will allow each person with epilepsy, attemtping to engage in employment or participate in community activities, to be able to afford the cost of the service.

2. The second area of service delivery would be appropriate mental health services which will be required by this population which has experienced the stigmatizing effects of rejection and being considered different because of the seizure disability. The rejection can be in the form of being denied employment and being denied the fundamental rights to participate in other community activities. At present there is a lack of knowledge on how to treat persons with epilepsy. Consequently, they do not receive adequate services.

3. The third area would be vocational and would require the person with epilepsy to have a right to prepare for employment commensurate with skills, abilities, and interests as do other persons in society. If the medical and psychological effects of epilepsy prevent this from happening, it is necessary that the appropriate service be established to overcome those

obstacles. Vocational preparation, educational opportunities, and transportation to and from the sites of those services must be provided.

4. Another service area that must be addressed is the development of persons to work directly with and within society. This is especially true of employers who require assistance to realize that persons with epilepsy can be employed and function as well as anyone else. They must also be shown that it is socially, morally, and economically acceptable to do so.

5. The fifth area of service delivery is the problem of housing and transportation. Currently, the reason why many people are unable to function in places of employment is that they aren't able to reach them (a transportation problem) and they have no place to reside. While various kinds of housing alternatives have been proposed for persons who are severely disabled or being deinstitutionalized, housing for the person with epilepsy is still a problem. Many private residences are afraid the person will have a seizure. Transportation is a problem since the person must be able to travel from where he or she lives to where he or she is working. Often persons with epilepsy have not achieved seizure control long enough to obtain a required driver's license, let alone the financial support to obtain an automobile.

6. The last service delivery is advocacy. While there have been national projects involved in this area, for the most part they cannot concentrate on local concerns. It is essential for there to be an accumulation of data. It does not help the person who needs assistance in obtaining a job or promotion to know that the area is being studied, but that no one can assist in the direct action of a particular need. Advocacy could fill this void.

B. Program Policy and Development: In order for the mentioned service delivery areas to be appropriately implemented, it is necessary for programs to be established and policy developed to make them a reality. Comprehensive and responsive services should be developed for persons with epilepsy. Optimally, it would be best if all of those service delivery areas would be provided to persons with epilepsy as they are to any other person in society. This is what the person with epilepsy would want most -- 'to be treated like anyone else.' In this way the medical services could be received at medical facilities that provide them to everyone else and medication should be available at a cost that is reasonable. Mental health services could be provided by any mental health professional who provides them to anyone else. Ideally vocational problems would be eliminated and the place of employment would be one where there is acceptance of the person with epilepsy as an individual who can work.

Since it is unlikely that this will happen as rapidly as desired and, since funding will not become that readily available to integrate persons into programs already in existence, there are varying levels of program development that must exist. While it is necessary to strive for the optimum, it is as essential to establish separate programs which deal only with persons with epilepsy and the problems they present. This may be the first step in addressing the problem. The person with epilepsy can be assisted by those specifically trained to address those problems. It is a beginning toward community acceptance and eventual employment.

The next phase of program development will include integration of the person with epilepsy into some of the existing services in the community. There will be less difficulty in doing so with medical facilities and some direct-service mental health systems which have individual impact. There will be much more resistance in the areas of vocational preparation, education, and eventual employment. In those systems the person with epilepsy will be mainstreamed with those without epilepsy. At that point, it is essential that a program be available to assist the person in coping with that adjustment or rejection. The need may be simply to deal with the issue "to tell or not to tell" about the "hidden disability."

A stronger program of integration into society can be established on the basis of program policy and development; however, it is totally dependent on the capability of those who develop program and policy to have significant impact on those who benefit from that policy.

Other aspects of program development that will be essential are participation in accrediting programs of service and establishing standards of service delivery whether this be for medical, psychological, or vocational services.

Another program area that must be developed is the one of "alternatives to employment." While this paper is primarily targeted toward those who are being prepared for competitive employment, there are many persons with epilepsy who are either underemployed or unemployed. According to the report of the Commission for the Control of Epilepsy and Its Consequences, of the over two million people with epilepsy, 25 percent of those of an employable age are either unemployed or underemployed. This rate is double that of the rest of the population. Programs must be developed to assist persons with epilepsy unable to function in competitive employment with the alternatives suggested for the rest of the disabled population. Assuming there is a continuum of vocational services from competitive employment to homebound employment, the person with epilepsy is entitled to receive those services. If, in that continuum, it is necessary for the person with epilepsy, because of the difficulties resulting from the combination of medical and psychosocial problems to receive such services, appropriate alternatives must be developed.

Another major area of program development is that of community participation. The definition of community participation can include the diverse activities of recreation, amusement, religious participation, education, access to insurance, health, etc. In order for the person with epilepsy to

benefit from those activities, changes must occur in both society's attitude toward accepting that person into the community of religious activities, recreation activities, and amusement. It will also be necessary for adequate insurance policies or programs to be established so that the person with epilepsy can obtain automobile, health, accident and life insurance. By prohibiting the person's participation in insurance programs, it is possible that the family will become economically deprived which also prohibits participation in community activities.

The last program area is perhaps the one that will cause the most difficulty in conceptualizing and implementing. Throughout most of the historical literature that is available on the problems of epilepsy, there is almost constant reference to the "epileptic personality." For persons who wish to make the distinction between the "epileptic personality" and the personality of any other disabling condition, note should be taken of the tremendous similarity of ingredients which compose the alleged personality. In the comparisons noted, there is no difference in the personality. Is it not possible that the person with epilepsy develops a personality in reaction to the way society accords treatment to that individual? Is it not possible that being rejected might make one behave in a way that causes many people to avoid social contacts? With all that society is accomplishing, might it not be possible to assist the person with epilepsy to develop a human personality?

C. Legislation: With the knowledge and understanding that program and policy must be developed, it will be necessary for certain legislative changes to occur in order to attain this objective. Some of the barriers to employment could be eliminated if legislation regarding discrimination in employment were enforced. Currently the legislation that has been written is not implemented for such varied reasons as lack of staff capable of dealing with the problem and lack of knowledge on the part of either legal advocates or self-advocates of bringing the problem to the full attention of the governmental regulatory agencies.

Affirmative action is law. The regulations have been written. The implementation of the regulations do not always take place nor are all employers covered by this particular policy. Some states have anti-discrimination laws describing employment and disabilities. This legislation should be as uniform as possible in all states and the enforcement mechanism established.

Another legislative area that has been accorded disability groups, but is not specific to persons with epilepsy, is that of 'accessibility'. While physical barriers such as stairs, curbs, and doorways are not as much of a problem, the incorporation of various safety devices would be extremely helpful so that if a seizure does occur, a person would not have to fear falling down an empty stairwell or inadvertently pushing a button or lever causing machines or mechanical devices to operate. Most of this legislation is based on Occupational Safety and Health Administration (OSHA) Standards as well as other federal laws. It does need to be enforced so that those activities can be made accessible to the person with epilepsy.

Perhaps one of the most important legislative changes that is recommended would be to change the financial support that exists for persons with epilepsy so they would receive money directly, rather than have it go to programs. Not only would it provide the comprehensive service that people need to function in employment and in the community, but it would give that overall feeling of independence if the funds to assist persons would be allotted to the person rather than the program providing the service. The thought that this might occur would be most helpful in that it would allow the person the freedom of choice as to which program to attend. It would certainly assist programs in maintaining those standards necessary in order to provide services on a competitive level. In addition, it would mean that the professional who assists the client in making decisions and finding appropriate services would become more responsive to the client rather than the system.

Most of the legislative changes are geared toward financial support and acquiring the person's right to function in society. Attaining this independence and equality should be a major function of the legislative recommendations.

Social Security Disability legislation should be amended so that if a person is disabled by reason of epilepsy, he or she can receive those benefits to which they are entitled. At this point, the determination of disability is at the discretion of whatever physician determines disability that day. The person with seizure problems is then put in a position of not knowing whether he or she is truly disabled or not disabled and whether he or she can be employed or not employed. Again, a consistent enforcement of current regulations specifically stated would be tremendously useful.

The person with a hidden disability, specifically epilepsy, may not be allowed to work because of the diagnosed condition. Assuming that person is adequately trained and prepared for employment, but is not able to become employed because of a societal attitude, a mechanism should be in place for that person to be able to sue society for depriving him or her of the right to a livelihood. While it is not possible to legislate attitudes, what is evidently the most effective control are the economic effects. The risk of financial threat might be one that assists society and employers to opening up their employment opportunities.

Along with this concept, might it not be possible for there to be financial incentives to employers who hire persons who have disabling conditions such as epilepsy? It would be necessary to assure that that person is adequately trained and skilled to perform in that specific job.

In this society, if one works, one is socially accepted and has a place. The benefits of eliminating those barriers to employment that currently exist would mean that the person with epilepsy would not only work, be self-supporting and contribute to society, but would also have a place in the community and be able to fully participate in the community, thus removing those barriers as well.

D. Research: Recently, the federal government was able to recognize the existence of valporic acid as a treatment for epilepsy. Persons who have been able to benefit from this needed medication were indeed pleased that recognition was finally given it after so many years of its being utilized in other countries quite successfully. There is a need for medical and chemical research, but there is an even stronger need to communicate findings so they can be used by consumers to function effectively in the community and employment. It is recommended that the funds used for research have a small amount set aside to disseminate research findings for proper utilization.

As important as the medical aspects of research, are those in the psychosocial areas. It is not necessary for persons to be put into control groups to discover which things might happen to them either by giving more or taking away less. What is important is that whatever studies of a scientific nature into the psychosocial aspects of epilepsy be constructed and conducted in such a way as to obtain the data that will enable the barriers of acceptance in the community and employment to be removed. If such studies will be funded, sums of money should be set aside so findings can be appropriately disseminated and utilized by persons with epilepsy and those who work with persons with epilepsy.

In the report of the Commission for the Control of Epilepsy and Its Consequences (4) there is an entire section devoted to research. Most of it relates to the prevention and control of seizures. It is medically based. There is little quarrel that the medical control of epilepsy can assist persons to function more independently. When this occurs, the person becomes 'normal' and society is accepting of that person's participation in the community and employment.

There is, however, one other area of research mentioned which is as important. The objective that the Commission has established for that research area is as follows: "precise information on the spectrum of employment of persons with epilepsy, including the number unemployed, those in non-competitive employment, and those in regular employment, as well as data on the basis of unemployment and specific measures required in employability." Obviously, if that stated research is implemented, it will be a tremendous assistance in overcoming not only the barriers to employment, but those barriers to participation of the person in community activities.

RECOMMENDATIONS

The following are general recommendations that have been alluded to in the discussion of the problem and its implications:

1. It is possible that by providing knowledge to people that fear, intolerance, and lack of acceptance will decrease. This is true for the professional community, the general public, and employers. Education to remove these barriers is essential not only in the training curricula for professional workers, whether they be physicians of technicians, but in developing public awareness

through a number of acceptable approaches, e.g. mass media, regional or local seminars.

2. Much attention must be placed on removing the barrier created by society's non-acceptance of its responsibility to making the community a place for all its members to function effectively.

3. In addition, it is essential for those persons who work for and with persons with epilepsy to make the efforts in preparation of data to the appropriate legislative bodies to obtain the needed changes as a mandate to society. It is not enough to obtain passage of legislation; it must also be enforced.

4. Funding and lack of funds for programs and individuals prevent development of appropriate service. Some funding mechanisms must be appropriately developed to provide services to persons with epilepsy.

CONCLUSIONS

The service delivery areas that were mentioned are not all those that affect persons with epilepsy. These are used primarily as examples of the kinds of problems that must be addressed. There obviously can be more programs and policies developed. To help all persons, including those with epilepsy, legislative changes and the development of research projects will be necessary to accomplish far beyond what has been stated.

The problem areas that were suggested and the possible remediation were not presented specifically in the expectation that these would be warmly received and implemented. It is expected that those truly concerned over what happens to members of our society will provide the solutions that will be essential to having persons with epilepsy function in society as normally as anyone else.

REFERENCES

1. Committee on Labor and Public Welfare. Subcommittee on the Handicapped. Rehabilitation and Developmental Disabilities Legislation. 94th Congress, 2nd Session, Washington, D.C., U.S. Government Printing Office, 1976.

2. Gordon, John E. (ed.) Developmental Disabilities: An Orientation to Epilepsy, Cerebral Palsy, and Mental Retardation. Philadelphia, Temple University Developmental Disabilities Center, 1975.

3. Levine, Irene. "Getting to Know the Epilepsies." Patient Care, April 15, 1977, pages 102-136.

4. Plans for Nationwide Action on Epilepsy. The Commission for the Control of Epilepsy and Its Consequences. Vol. I, H.E.W., Public Health Service, NIH, 1977, 1978, page 45.

5. The Role of the Sheltered Workshop in the Rehabilitation of the Severely Handicapped. New York: Greenleigh Associates Inc., 1975.

6. Shahed, A., S.M. Bruyere, and G.N. Wright. The Assessment of Human Service Needs of Persons with Epilepsy and Cerebral Palsy. Wisconsin Studies in Vocational Rehabilitation, Series 3, Monograph XVII. Madison:University of Wisconsin, Regional Rehabilitation Research Institute, 1975.

7. Stripling, T. The Developmental Disabilities Program. Federal Programs Information and Assistance Project. (54-P71180/6-02).

8. Wright, G.N. (ed.) Epilepsy Rehabilitation. Boston:Little, Brown, and Co., 1975.

CHAPTER 4

EPILEPSY: ACTION FOR IMPROVING SOCIALIZATION AND FAMILY SUPPORT, AND REDUCING STIGMA AND NEGATIVE ATTITUDES

Author: David I. Mostofsky, Ph.D.

"The paper supports my conviction that a total person approach will go further than any piecemeal method. Medication control (of seizures) plus optimum mental health will probably result in the best seizure control and functioning within the environment. I further agree that the patient himself and those professionals with whom he/she has contact are a primary influence and factor in adjustment.

Not unlike all other diagnosed conditions, the handicap is influenced significantly by the emotional, environment, social factors and that well-coordinated services by trained individuals make the difference. As the paper suggests, reactions by others "teach" behavior which is often inappropriate. This would suggest that, upon diagnosis, not only the patient but the family should be involved in 'treatment' or preferably a program of learning how to deal with the new situation.

The concept of respite is an important one particularly if the respite is an environment which urges growth and independence. Once again this should not be limited to the patient's rest from the parent or significant others, but an opportunity for all people involved to be separate and to pursue personal growth.

Rehabilitation personnel, specifically Rehabilitation Counselors, could provide the individual comprehensive approach necessary in serving this population. Legislation recognizing this profession would probably allow for increased and broader funding for these services."

Excerpts from comments by Joyce Pigg, C.R.C.

Persons with epilepsy suffer from the consequences of recurrent, abnormal electrical discharges from nerve-cell aggregates in the brain. The pathophysiology creating this paroxysmal electro-neurophysiological condition promotes, cognitive, or affective changes which may last from a few seconds to several minutes (in most cases). The changes need not appear to the observer as ugly convulsions (although they may); they need not be more than transient interruptions in normal activity (although they may); they need not lead to alterations in mental health or personality (although they may). The valiant efforts to create an image of normalcy about the disorder are overwhelmed by age-old prejudices and ignorance. Although it is true that some epilepsies can mean deterioration and can be fatal, these incidences are rare. But

in the public mind, and often the patient's, it is these very infrequent occurrences which strengthen rather than weaken such irregular and unpredictable associations. The prevailing reaction is to reconstruct, in the mind's eye, the epileptic fit as "an excursion through madness into death" (Taylor, 1973). The cold, hard facts of epilepsy may be communicated, and many social and political injustices may be remedied, but the stigma of pills, the restrictions on activity, the days missing from school or work, the occassional injury and the sense of helplessness remain. Indeed, the effort to create an image of normalcy about epilepsy may be misguided. As a symptom-complex it is strikingly different from most other medical disabilities, and the issues of concern in this seminar cannot be simplistically considered as the psycho-social sequelae of an organic disorder. As I will argue in this position paper, the very essence of the disorder is at once neuro-psycho-social; a view which is, perhaps, still uncomfortable in the thinking of both medicine and rehabilitation. If this position is tenable, then it will not be difficult to recognize that the problems of seizure control and those of personal functioning and quality of life are intertwined. Our current understanding of either is dismally inadequate, but we are becoming increasingly convinced that solutions to the problems of epilepsy will not be found alone in a space-program mentality which searches for the magic drug, nor in adding numbers to the corps of job counselors. The cycle of environment and soma which feed on each other must be entered, and it will not do simply to hope to break the chain where soma affects psyche, but we will have to learn better how to make environment change the physiology. This is not science fiction. We have reviewed elsewhere the evidence for such possibilities (Mostofsky and Balaschak, 1977), and they are real and present. Behavioral interventions for the clinical control of seizure disorders are available. Psychotherapy, behavior modification and cortical feedback programs have all been demonstrated to offer valuable avenues for "anticonvulsant" support. These activities may be pursued by physicians, psychologists, and rehabilitation specialists. I wish to assert that a reconceptualization of both the pathophysiology of epilepsy and its management is critical to an appreciation of the "hidden" nature of this disability, and to the thoughtful planning and policy formulation for treatment and rehabilitation programming.

The traditional view in both medicine and the social/behavioral sciences is clouded with ambiguities and inaccuracies. Let us briefly consider the strict neurological view of epilepsy. Physicians are taught the general dynamics of the epilepsies and their medical management. Neurologists and epileptologists gain particular expertise in this area, and the skill to properly administer and interpret EEG examinations. Patients are eventually categorized into one or more entries of the International Classification (e.g. partial seizures, complex seizures, simple symptomatology, etc). The resultant diagnosis, however, fails to reflect much of the truly crucial information which the problem of epilepsy presents. Ultimately, the patient's problem is not the spike and wave discharge in the EEG; it is the disruptive and functional impairment in his/her behavior. (It should be noted that abnormal EEG's may be unaccompanied by any clinical symptoms). The International Classification is extremely valuable in helping towards standardization and an understanding of neuroanatomical locus and neurophysiology, as well as providing valuable predictive data about the efficiency of the individual anticonvulsants when

prescribed for the respective conditions of the epilepsies. It does not tell us, however, whether three petit mal attacks are "worse" or "better" than one grand mal; whether a patient's condition will be "controlled" by medication, etc. Indeed, the criteria for control by the physician may be at total variance with the patient's estimate. For while, a physician may be justifiably pleased that a drug program is able to contain the seizure problem to a few petit mal episodes a day, neither the patient nor his/her family may regard this as satisfactory. The fault is not the classification system--but left with this ambiguity, how are we to interpret the popularly accepted statistic that "80% of those with epilepsy have some seizure control" without knowing how this figure was derived?

From the psychosocial front, we are continually assaulted by studies, epidemiological data, and conjecture with varying degrees of rigor. We are reminded that the concept of "an epileptic personality" is both wrong and vicious, while we are simultaneously invited to hear and read results of psychometric investigations which yield statistically significant findings, in addition to the classic paper by Tizard (1962) the more recent review by Hermann (1977) deserves attention. Apparently persons with epilepsy do have real--if not irreversable--psychological problems appended to their woes, though to be sure not a characteristically "epileptic" one. One could hardly expect less--for any organism so attacked would be predicted to adapt to the harsh and aversive environment, if only "maladaptively". The selected examples are presented to dramatize the fragmented approach to problem solution resulting from a dualistic formulation of the problem. The problems are, to be sure, real and responsive to solution, providing that one is not a slave to either a parochial "organic view" with mental health overtones, nor to a parochial "psychosocial disorder view" residing in a neurochemical organism. My conviction is that a reassessment of our conceptualization of the epilepsy problem, in the context of a joint medical (drug-organic) and psychosocial (therapy-psychological) entity, is propadeutic to meaningful gains. I believe that we can do more to control seizures for all patients (especially for those whose condition is unsatisfactory). Once controlled, the personal functioning of the patient and his acceptability to others will be correspondingly improved. I believe that the patient can be taught to be a therapist for himself/herself, that our environment and its consequences modulate the course of seizure activities, and that rehabilitation and counseling specialists are central therapeutic agents in this enterprise.

COMPREHENSIVE MANAGEMENT

I have discussed elsewhere (Mostofsky, in press) the need to appreciate the separate dimensions of illness following an analysis by Taylor (personal communication). In that formulation, each of the dimensions - disease, illness, and predicament - define their own territories in the diagnosis and treatment of a sickness. The disease portion is concerned with a physical reality: not judged morally, sometimes even trivial, sometimes producing no symptoms of consequence. The illness portion represents the functional constraints on behavior: not depending on disease for its validity where space, place, and time modify its significance, where diagnosis does not relate to specifiable structural or functional changes of a physical reality, and where personal change is important.

Predicament is that portion of sickness in which a complex of social ramifications, with immediate bearing on the individual, must be dealt with. When, therefore, we are concerned with vocational opportunities for persons with epilepsy, we are in the main concerned with illness and predicament. When we move to insure socialization and family support, the elimination of social and community barriers, the financial stability and adequate health care, we are concerned with illness and predicament. The background rhythm of the EEG may or may not change as a result of our actions, but hopefully the symptom profile and the living style profile will be substantially altered. It would seem imperative that family, employer, teacher,and patient be drawn into the rehabilitation effort from the moment of diagnosis. The roles of the separate participants can then be clearly identified and the necessary competencies acquired. The breeding ground for costly and damaging stigmata and attitudes may be controlled at its source. And where a multiple handicapping condition exists, all concerned will be better able to orchestrate the many talents and services which such special needs demand. Without appropriate coordination, nor properly trained specialists, the patient and family are doubly victimized.

THE NATURE OF DESIRED SERVICES

The responsiveness of seizures to environmental and intra-psychic conditions has direct bearing on the design and delivery of rehabilitative and counseling services. Both leisure and work situations must be conducive to alleviating the client's plight. Rewards and support for desirable behavior must be available and administered; non-reward and response cost for inappropriate behavior (including the seizure) should be programmed; and secondary gains for seizures should be eliminated. As part of our intake procedure, we ask our clients a series of questions to help us establish the relative positive and negative consequences of having seizures. We ask such things as "what happens when you have a seizure?" "What does your mother do?" "What does your father do?" "How does that make you feel?" "What is the worst thing about having seizures?" What is the best thing?" "How many seizures a year would you like to have?" The answer to the last question is not invariably "none". Having a seizure can be quite an effective way for a child or adult to become the center of attention; to cope with stress and avoid defeat by creating a situation where the teacher, parent, or employer feels quilty for their action in having precipitated this unfortunate outcome. Perhaps, too, feeling guilty they will vow to avoid such encounters in the future and, despite any liberal or enlightened view of epilepsy, to avoid having to deal with people with this strange disorder. Vocational opportunities and interpersonal living are given serious setbacks, for one is much more likely to remember the seizure, than the many hours of contact in which normal, if not delightful, relationships are maintained. In addition, we have not yet learned the value and importance of making asylum and respite care available for simple refuge and escape. The sheltered environments and hospitalization options, as we currently know them, are inappropriate for refuge for most people with epilepsy who need such alternatives. Not infrequently, the wise medical consult to a refractory problem in epilepsy appears as "Recommend parentectomy, i.e., get the kid away from his parents". The vicious cycle of family being overprotective and the client being passive-aggressive rises to a crescendo, and the need to get away to neutral ground is unmet. Models for such facilities do exist in several European

communities, and we would do well to emulate them. To assure such social change, we need to turn out a better epilepsy-educated citizen from our colleges and professional schools. For they are the teachers, parents, spouses, physicians, politicians, and counselors of tomorrow's society. We need continued monitoring and empirical evaluation of the life style and needs of this population (c.f. Perlman, 1977, Rodin et al., 1977). State and federal government must assure financial support and recognition for both demonstration and basic research, while government should provide meaningful leadership in mainstreaming persons with epilepsy whose talents and abilities would otherwise qualify them. In particular, the regulations by the Department of Defense which deny enlistment of persons with epilepsy to the armed forces (a policy which, incidently, is supported by the Medical Professional Advisory Board of the Epilepsy Foundation of America) is both anachronistic and regretable. The opportunities for career training, proper medical supervision, socialization, etc. are probably unparalleled, and the security of the country or the efficiency of its fighting force would hardly be jeopardized by employing persons in non-combat roles which are equivalent to their civilian counterparts, as is done in other countries. For those not choosing continued service in the military, the services of the Veteran's Administration (V.A.) would allow a level of health care which many would not otherwise realize.

CONCERNS ABOUT ATTITUDES

Our interest in attitude change as a practical matter, is motivated largely by our faith that the attitude fuels the action. Certainly the attitudes surrounding the epilepsies and the person with epilepsy are remarkable for their negativism. "The history of epilepsy (probably the longest history in medical literature to which any single disease, unless it can be malaria, can lay claim) might well be said to stand as a monument to human error, to human fallibility; as lamentable evidence of the unnumberness of those whispers of fancy to which the human mind has ever listened with credulity" (Bunker, 1947). Fortunately, attitudes have been changing for the better, as one compares surveys taken over the last several decades.

But there is a fundamental issue which has long been conveniently overlooked by many who have aggressively petitioned for assigning a high priority to the need for bringing about changes in the public's attitude toward epilepsy. The late Professor Thurstone, the father of attitude measurement, insightfully observed that "an attitude is what your stated verbal expression is". If you are asked to state your attitude about smoking, you may say it is bad. If you were later found lighting up a cigarette, does that invalidate your attitude? Not at all. There could be a myriad of reasons to account why in fact, you engage in smoking, and at the same time hold to an attitude that smoking is bad. I am not sure that what we really want is attitude change. I think what we want is behavior change. We can, perhaps, change the attitude of employers and they will fill out a questionnaire three months from now, after we have spent a million dollars on a public awareness campaign, and they will tell you their attitude is "yes, oh fine, epileptic? yes". The employer may even hire one with epilepsy and the first day he/she has a seizure, the employment is over "not because I have anything against epilepsy, but he can hurt himself" or "the people around here are uncomfortable". We have gotten the attitude change, but

we haven't gotten the behavior change that we wanted. We can delude ourselves into thinking that attitude changes are going to make the difference. We are spending fortunes on public awareness campaigns for smoking. I am not impressed, however that the attitude change is having significant impact on the sale of cigarettes and tobacco; nor am I not impressed with the attitude change outcomes on the 55 mph speed limit. Few people will argue that it is a safer and saner speed, but the data on the highways belie these sentiments. Indeed the correlations between attitudes and behavior have been disappointingly low.

Perhaps in our zeal to correct and to help we may have, like the guns of Singapore which faced the sea rather than the land, left our more important frontiers unguarded. McClelland (1978) has recently emphasized the "oversell" which accompanied the inability of social scientists to deliver the contracted outcomes, although they had mastered, and refined sophisticated procedures in attitude and motivation research. This has been the case, as well with the relationship, between client contact and attitude towards disabled persons (Kepth, et al., 1969, Keith, et al., 1969). To my knowledge, attitudes regarding epilepsy among practicing or aspiring counselors have not been determined. If only as an exercise in curiosity, (but with a serious mission to use the information as a platform for drafting and implementing changes), it might be worthwhile to pose the following questions to such an audience of professionals:

1. Does the thought of seeing a client going into a seizure scare you?
2. Do you have an interest in finding more information about epilepsy?
3. Would you be willing to counsel a handicapped person, knowing that he or she has epilepsy?
4. Have you ever witnessed an epileptic seizure?
5. Do you feel that you know enough about epilepsy or need to know more?
6. Could you tell if a person was having an epileptic seizure? Petit mal? Psychomotor? Grand mal?
7. Would you stop to help someone having a grand mal seizure? What would you do?
8. Do you feel that persons with epilepsy require special counseling aside from any other handicaps they may have?
9. Would you think any less of a person if you found out he or she has epilepsy?
10. Do you think that your counseling can impact your client's seizure problems?

I have the impression that rehabilitation has taken an isolated stance from the epilepsy problem. The counselor often regards it as another client to work with who has an ugly disability, "and I don't know a damn thing about it; I hope the hell he doesn't have a seizure in front of me". Agency supervisors report that it is not at all uncommon for somebody to have a seizure in the presence of a counselor, and the first thing the counselor does is to panic or to say to the client: "do me a favor. Go downstairs, have a seizure someplace else. Don't have it near me because I really don't know how to handle it; or I don't want to have anything to do with it". The client is basically shuttled along the way because of the discomfort of the counselor even to be in the presence of the person with the epilepsy, let alone try to deal with it in a therapeutic manner.

I think that this isolation from the problem of epilepsy is predicated on a few improper assumptions; one being that somehow rehabilitation specialists are beyond the pale of therapy, (and I am trying to assert that indeed he/she is a therapist, even if only counseling at a vocational level or providing an integrating and coordinating social service at any agency level).

A MODEL FOR THE CREATION OF CLINICAL INTERDISCIPLINARY TEAM EFFORTS

Among the chronic problems of the disabled, certain conditions stand out because of their sheer number, enormity of dysfunction, and staggering cost to the nation. Of these, the one most immediately amenable to effective treatment and with most promise for rehabilitation, prevention, and cure, is epilepsy. Yet, this disorder has traditionally received less public and private support and understanding when compared to other chronic disorders. This neglect can, in part, be explained by the fact that the problems of epilepsy and of the client are so diverse and complex, and several dimensions of the problems involved are poorly understood.

Over the past twenty years or so there has been significant progress within primarily the medical fronts in epilepsy. Several of the more sophisticated medical centers have developed units with professionals highly skilled in the epilepsies. Often working as a multi-disciplinary team, they have been able to bring some of the benefits of progress to their clients. Some instruments to reach wider target populations have been evolved by both State and private agencies. Yet, it is generally recognized and often documented that such potentially effective skills reach only a minority of the population in need. This is particularly true for large groups of clients who live in culturally, economically, medically deprived or under-served communities, not solely in the most economically deprived and socially disorganized urban zones, but also in the suburban, more affluent communities. The problem is not only that a group of those with epilepsy may go unrecognized, but for those who are known (a) the facilities most readily available to them are often substandard; and (b) those with greater sophistication may be inaccessible either for economic reasons, lack of manpower and often mistrust, (not wholly unreasonable, by the consumers towards the most prestigious institutions). In fact, even in these, though specialized facilities exist for some clients, a greater number of patients reach outpatient or emergency clinics where they meet the least sophisticated medical service and supervision, and the least care for their total management and rehabilitation.

Because of the complex nature of this disorder and the public's historical attitudes towards it, serious neglect has continued in the educational realm. Not only is this information gap found among physicians and nurses in the community, but is also true for social workers, counselors, teachers, and others who could be instrumental as the specialist doctor in recognizing and applying their special skills, i.e., skills in remediating or preventing many of the non-medical needs and problems of those with epilepsy.

There is no obvious panacea for the resolution of these and other problems confronting the battle on epilepsy. One area that appears amenable to some improvement and the one on which a proposal such as this is focused, viz. the

planning and implementation of "collaborative programs" geared towards goals and objectives such as the following:

a. Models of Excellence for the diagnosis, treatment, rehabilitation and comprehensive long-term management of epileptic subjects.

b. Models of Excellence for the training in the various aspects of epilepsy of community people - including physicians, social workers, nurses, counselors, community workers, teachers and others.

c. It is conceivable that such Models can be planned and implemented simultaneously through Inter-Institutional and Agency Collaborative Efforts involving a few senior specialists in epilepsy and with the following further objectives in mind:

    1. The evaluation and treatment of some twenty to thirty patients in depth -(per model setting) providing them not only with the usual medical services available from senior level personnel, but also providing them with more subtle, more continuous multi-disciplinary efforts of various professionals from the institutions involved.

    2. The involvement of several community persons at each step, beginning with the initial evaluation (neurological, laboratory, psychological, etc.), and the necessary longitudinal follow-ups to be provided at the institutions involved. In addition, they should actively participate in formulating short- and long-range plans for the full management and rehabilitation of the client.

    3. These community persons, assigned to each case, would be involved on a longitudinal time scale with the senior neurologists at the institution. In collaboration and consultation with them, the community persons will take on various responsibilities at the local level.

    4. In the case conference format, the use of various on-going teaching devices at the institution, becoming familiar, within a reality-oriented context, and a variety of the issues involved in a long-term follow-up of clients, these community people (be they nurses, community workers, physicians, etc.) would receive structured, effective in-service training in epilepsy.

    5. This objective, if effectively reached, would produce a number of community persons who will have developed skills in the area of general advocacy for epilepsy and for providing education for local school personnel, various agencies, employers, and the general public at large; in behalf of the client.

    6. As a corollary objective, they will become skillful in case finding by detecting the unknown people with epilepsy, and will facilitate accessability to more appropriate care facilities of those known

to have epilepsy receiving sub-standard services. They will be able to advise other paraprofessionals, administrators, and colleagues on the care and treatment of these clients.

d. It is expected that the participating neurologists and appropriate consultants and coordinators would be better informed to reach some final assessments of the strengths and weaknesses of community programs and resources for those with epilepsy in the various States and to formulate specific recommendations for further action by the respective Local, State and Federal agencies.

The essential features of these recommendations highlight:

1. The collaborative nature; namely that the goals and objectives outlined should represent the combined effort of a number of recognized professional specialists in epilepsy.

2. The model emphasizes the combination of in-depth service to a few selected clients on a longitudinal time basis, before large scale implementation is possible.

3. A structured program of in-service training for a sample of community people is centrally integrated into the model. These aspects in fact fulfill a number of needs:

    1. getting together a number of senior professionals with varying backgrounds and philosophies, to achieve cross-fertilization of ideas and contributions;

    2. by following intensely a few clients over a period of several years obtaining some greater insight for the entire team on the strengths and weaknesses of existing programs for the client;

    3. reaching out for professionals and paraprofessionals in the community for training in epilepsy and creating a core of "involved" advocates and specialists for the large number of subjects;

    4. the client gets a sense of excellent care; the M.D. becomes more sensitized to community problems, and to the services which he/she can expect from other professionals, and the counselor's contribution to the larger client management objective becomes more visible and important, as it deserves to be;

    5. beginning of a program for more meaningful roles by lay organizations;

    6. providing an assessment over a defined period of time of the "state-of-the-art" in epilepsy by the participating professionals and appropriate consultants; creating the beginning

of state-wide and regional collaboration.

A program such as the one outlined here has in fact, been undertaken at the Children's Hospital Medical Center (Boston, MA). In this instance, the impetus for its design and character was shaped jointly by the chief of service and a social worker/counselor. Such a model can indeed succeed and deserves to be replicated in similar hospital settings throughout the country. More importantly, the model (or some variation of it) deserves the attention of rehabilitation and community health providers, as well as special educators and agency representatives, as a viable effort to bring about desired improvement in both the welfare of the individual client and the system in which he/she finds themselves. I would imagine that Rehabilitation Counselors are particularly well suited to activate such model programs and to encourage participation in them by their colleagues. They have not yet been adequately represented in such efforts.

THE REHABILITATION COUNSELOR AS ADVOCATE

The scene is not totally dismal. There are many resources in the community although there is room for more. There are competent service deliverers, but there is room for self-improvement. Imaginative programming via the network of Chapters in the Epilepsy Foundation has begun, and the rehabilitation expert can offer much in the way of consultation and conscience. The report by the National Commission for Epilepsy will undoubtedly garner for the cause of epilepsy a level of visibility and receptivity by people in high places not heretofore achieved. The counselor should exploit the opportunity to demand of agencies, volunteer societies, and foundations the support necessary to introduce new elements in our social order and to properly utilize those which exist. It will be the voice of a respected advocate, forcefully claiming the right of the client to enjoy a better personal life, and whatever stigmata or negative attitudes persist will surely decrease as the client regains control over the seizures and his/her personal growth. I would argue against institutionalizing such change; against attempting to achieve <u>these</u> goals by legislation. Ours has been the culture where we outlaw undesirable things or rules, rather than change the behavior of those who use them or who control others to live by them. Pollution, drug abuse, crime, and the injustices suffered by these clients are problems of people, not things or inanimate systems. But legislative and administrative remedies can be effectively applied to certain areas where change might not otherwise occur.

The cost effectiveness of bringing one with epilepsy to enjoy life, to be gainfully and happily employed far exceeds any subsidized governmental program. This will require insurance carriers to recognize the need to adjust reimbursable payments for short-term hospitalization for behavior or dynamic therapy treatment (for the epilepsy - not as a mental health benefit!) This will require hospitals to staff their epilepsy clinics with therapists and counselors; professional schools to better train their professionals about epilepsy and how each of them has a potential role as change-agent; advocates to advocate effectively and parents to parent normally. In the face of our passion to do good, we must however proceed with caution. We need considerably more quality research. At the very least, we need the possibility for adequate funding

for research of questions with a conspicuous risk of failure or which run against the grain of accepted positions. There does not now exist adequate possibilities for demonstration or basic research efforts in experimental psychology or cortical biofeedback with the necessary level of support, unless such monies can be carefully subterfuged piecemeal in the budgets of other "priority" fundable proposals. We need accountability for what we say and do. This requires looking behind the labels and the stereotypes to the issues. The main difficulty is that the more complex the problem, the more pressure there seems to be to find simplistic solutions. Let us do our best to avoid yielding to that pressure.

IMPLICATIONS FOR ACTION

SERVICE DELIVERY

-- There is a need to assure that those with epilepsy are able to receive adequate medical and psychological care.

-- There is a need to attract counselors, teachers, family, and others as part of the "therapeutic" effort.

-- There is a need to establish inter-disciplinary "Family Service Teams", staffed by experts knowledgeable in the subtleties of the epilepsies, as part of neurological and seizure unit clinics.

-- There is a need to begin vocational counseling for clients during early adolescence, so that realistic expectations for career selections will be possible.

-- There is a need to assure quality services in EEG and GLC (gas-liquid chromatography) laboratories and in psychotherapeutic and educational settings.

-- There is a need to make provisions for the development of asylum - for appropriately structured settings of work, leisure, and residence.

-- There is a need for regional cooperation and collaborative enterprises.

PROGRAM AND POLICY DEVELOPMENT

-- Curricula, especially in schools for professional training (RN, Ph.D, Ed.D, M.D.) must be able to equip their graduates to deal with the range of consequences of epileptic disorders.

-- Seizure control programs and evaluations must be extended to populations in prisons and other institutionalized settings.

-- Collaborative teams with interdisciplinary representation must be formed to better achieve case finding, assurance of service delivery and advocacy.

-- The responsiveness of seizures to environment and personal dynamics requires serious examination and a fair opportunity for evaluation; the trans-

formation of stereotyped roles from teacher, parent, spouse, or counselor to that of therapist must be appreciated, and agency activities correspondingly adjusted.

-- Epilepsy Centers with a pronounced psychosocial emphasis should be developed to complement the existing facilities which devote their efforts to the biological aspects of the problem.

-- The support of research and training should be included under the Rehabilitation Research & Training Center (RTC) programs funded by the Rehabilitation Services Administration (RSA) of HEW and already in existence.

LEGISLATION

-- Third party carriers should accommodate coverage for non-traditional "medical services" rendered to effect seizure control.

-- Entry to the armed forces should not be denied to persons with epilepsy.

-- State Councils of Developmental Disabilities should, as mandated by Federal Acts, aggressively pursue the interests of persons with epilepsy. Token statements in State Plans should not be accepted as satisfactory.

-- Findings and recommendations of The National Commission for Epilepsy and its Consequences (1978) should be implemented.

RESEARCH

-- Delineation of the effectiveness of the behavior therapies in epilepsy should be undertaken and clinics should be established as adjuncts to neurological departments.

-- The clinical usefulness of cortical biofeedback in controlling seizures should be studied with adequate support.

-- Research in animal analogues of the epilepsy problem, particularly studies examining behavioral interactions with chemical and anatomical variables, deserve priority support.

-- Development of a taxonomic structure for the epilepsies which may go well beyond the International Classification should be undertaken. Multivariate analytic procedures should be applied to many studies which would normally generate voluminous univariate tabulations.

-- Cross cultural studies of epilepsy and the forces which operate to alleviate or exacerbate the seizures should be carefully investigated.

-- Studies concerned with attitudes and stigma should be accompanied by strategies for assuring the behavioral changes which are implied.

REFERENCES

1. Bunker, H. A., Epilepsy: A brief historical sketch. In P.H. Hoch and R. P. Knight (eds). Epilepsy, N.Y. Grune and Stratton, 1947.

2. Hermann, B. P., Psychological effects and epilepsy: a review. American Psychological Assoc. Journal Supplement, MS. 1430, 1977.

3. Keith, E., Palmerton, R.M. Framkin, Perceptual and Motor Skills, College Counselors Attitudes Toward Education Considered a Determinant of Attitudes Toward Disabled Persons, 1969, 28, (434)

4. Kepth, E., Palmerton, R.M. Framkin, Perceptual and Motor Skills, Contact with Disabled persons and Intensity of Counselor Attitudes, 1969, 28, (434)

5. McClelland, D. C., Managing motivation to expand human freedom. American Psychologist, 1978, 43, 201-210.

6. Mostofsky, D. I., Paroxysmal disorders of the central nervous system. In Turner (ed.) "Handbook of Clinical Behavior Modification". J. Wiley, N.Y. (in press).

7. Mostofsky, D. I. and Balaschak, B. "Psychobiological Control of Seizures" Psychological Bulletin, 1977, 84, 723-750.

8. Perlman, L. G., The person with epilepsy: Life Style, needs, expectations. National Epilepsy League, Chicago, IL, 1977.

9. Rodin, E. A., Shapiro, H. D., and Lennox, K., Epilepsy and life performance. Rehabilitation Literature. 1977, 38, 34-39.

10. Taylor, D. C., Aspects of seizure disorders: II On prejudice. Developmental Medicine and Child Neurology, 1973, 15, 91-94

11. Tizard, B., The personality of epileptics: A discussion of the evidence. Psychological Bulletin, 1962, 59, 196-210.

SUMMARY OF IMPLICATION FOR EPILEPSY REHABILITATION

The specific recommendations which follow represent concerns which organize themselves around two major, and not necessarily mutually exclusive, objectives for action:

(1) Comprehensive and Interdisciplinary Management of the Epilepsies.

This implies requisite development and refinement in the areas of training, research, program development, service delivery, monitoring and the implementation of rehabilitation planning beginning at the time of initial diagnosis or case discovery and continuing with support as may be required.

(2) Legislative, Regulatory and Political Remedies. This implies the re-examination, development of regulations which permit the establishment and delivery of desired support services: The machinery to utilize, with maximum efficiency, the provisions of existing policies and service systems, and the necessary funding to assure the ability to train, study, and provide the available services which are sought.

SERVICE DELIVERY NEEDS

Early intervention (case finding) should be stressed in order that the psychosocial problems be minimized and dealt with as they arise in the educational, community and vocational areas of the client's life. The development of coping skills, as early as possible, should be one major goal.

Early case finding should include the school setting, rather than the usual post-high school referral of the client with epilepsy.

It was recommended that every medical center, hospital and community have medical expertise for diagnosis and treatment of the epilepsies.

The "counseling" aspect of the Rehabilitation Counselor's functions needs to be re-emphasized.

Due to the pronounced stigma associated with epilepsy, delivery of services may require (a) smaller caseloads due to employer resistance, and (b) supplementary employer education programs.

Aspects of the Education for All Handicapped Children's Act need to be better utilized, e.g., one section of the Act allows persons with epilepsy to benefit from the comprehensive evaluation and training.

There needs to be an emphasis on work adjustment and transitional programs to assist the client in entering the mainstream of society. In this case, habilitation would be the most appropriate phase, since for some clients, full potential has never been realized.

More effective systems of follow-up and post-employment services need to be developed by the rehabilitation agency to insure better and longer-lasting job placements.

Vocational accessibility warrants attention by the Rehabilitation Counselor. Since many persons with epilepsy cannot get a driver's license, the factor of mobility and access to transportation must be developed and understood in the individual's plan of rehabilitation.

PROGRAM AND POLICY DEVELOPMENT NEEDS

It is necessary to establish additional Comprehensive Epilepsy Centers which regard equally the medical, psychosocial and vocational aspects of those with epilepsy.

The Rehabilitation Services Administration (RSA) should consider the development of a Research and Training Center (RTC) which focuses on epilepsy.

Medical services need to be upgraded, especially in the area of emergency room services, communication and referral linkages with existing (and future) Comprehensive Epilepsy Centers and access to quality laboratories for medication screening evaluations.

Training programs, including continuing education for Rehabilitation Counselors, should emphasize the attitudinal and psychosocial aspects, as well as general knowledge about the epilepsies.

More multidisciplinary training conferences are needed (on a regional and periodic basis) in order to focus on the team effort, which is mandatory if the handicapping effects of epilepsy are to be minimized.

The concept of "presumptive eligibility" for rehabilitation services is recommended, i.e., presume that all newly diagnosed cases of epilepsy will require some array of services that already exist (or may still be in some stage of development) to assist the client in reaching the highest level of functioning.

RESEARCH NEEDS

The Rehabilitation Services Administration (RSA) should establish and support a Research and Training Center (RTC) with a core area of Epilepsy Rehabilitation.

Basic behavioral research is encouraged in the following areas: psychosocial support groups for clients, using peers and parents, biofeedback, early intervention approaches, determinants of rehabilitation success and the study of approaches to reduce stigma and foster employer acceptance.

Research is urged for methods designed to reduce negative attitudes on the part of all professionals, as well as the general public and patients themselves.

There is a need for research into identifying the social problems unique to those with epilepsy, with the goal of systematic techniques for solutions.

A review and analysis should be undertaken of cultural implications of family, client and community in understanding and dealing with epilepsy and its vocational and social consequences.

Research utilization and dissemination models are recommended in order to keep rehabilitation personnel current as to the latest in advances in serving the person with epilepsy.

LEGISLATIVE NEEDS

Relevant legislation is in need of constant monitoring to insure that the intended delivery of services is properly implemented.

Current legislation and regulations having sections discriminatory to persons with epilepsy is in need of amendment and/or a new statute, e.g., the areas of driver's licensing, insurance and armed services.

When programs for various rehabilitative services are legislated, lawmakers are urged to provide the monetary resources to do an adequate job in serving the client.

OTHER POINTS-OF-VIEW

The following recommendations represent the views discussed by a specific Mary E. Switzer Fellow at the Seminar and, while it may not have been adopted by the entire group, is presented as another viewpoint which may foster continued thinking on the subject.

For the mental health needs of the client, mental health support personnel should be attached to epilepsy rehabilitation programs rather than requiring the client to seek mental health support from another (mental health) agency.

Vocationally relevant continuing education for neurologists should be explored since this may be even more important than neurologically relevant continuing education for Rehabilitation Counselors.

Consideration is recommended of the development of more "shared jobs" or the expansion of a "piece-work" approach for those clients who, due to seizures, may not be able to sustain a five day/eight hour schedule but could function with less demanding time requirements.

Appropriations from the National Institutes of Health (NIH) agencies should consider a greater proportion of funds for essentially non-medical research, which has usually been minimal.

To help overcome employer resistance, the use of tax credits for hiring a person with epilepsy should be explored. In addition, legislation to encourage greater employer flexibility for "shared-job" arrangements may also merit investigation.

CHAPTER 5

CARDIAC ILLNESS: ACTION FOR REDUCING BARRIERS TO EMPLOYMENT AND COMMUNITY PARTICIPATION

Author: Matthew Maxon, M.A.

"The first part of this paper presents a general overview of cardiac rehabilitation, its incidence rate, and some areas of progress that have been made and the general 'state of the art.' The discussion also relates to the psychological adjustment process to a cardiac disability, employment barriers, social barriers, and suggested areas that need further investigation.

Mr. Maxon makes some good points and stresses the need for changes in behaviors of vocational rehabilitation agencies in dealing with cardiac disability. He also indicates that there needs to be a change in the financial disincentives of Workmen's Compensation and Social Security Disability benefits. He makes some excellent points regarding the vocational placement process for persons with cardiac conditions.

Vocational rehabilitation counselors must be involved in the cardiac rehabilitation process early in order to "head off" financial disincentives such as pension plans, Workmen's Compensation, Social Security Disability benefits, and other reasons why persons do not return to work after having a cardiac crisis. The Vocational Rehabilitation Counselor needs to take a strong role with the employer and unions so as to make the proper medical/vocational interpretations on the person's ability to return to work. The role of a vocational rehabilitation counselor cannot be over-stressed as they can assist persons to return to work and facilitate reemployment as outlined by Mr. Maxon.

Early intervention by vocational rehabilitation with this client should be encouraged, and the interpretation of when rehabilitation starts and the acute condition stops should be defined as when rehabilitation type services are provided after the person leaves the coronary care unit such as physical therapy, social work intervention, dietary modifications, etc."

Excerpts from comments by Hank E. Graden, C.R.C.

"An excellent case is made in this paper regarding the multi-faceted problems faced by the cardiac patient. Of great concern to me is the fact that vocational rehabilitation services have actually decreased to this population since 1970. Consequently, the vocational rehabilitation program must stop and take a look at what it is doing and develop strategies to increase service to this population.

"The paper has raised a number of issues which will require considerable attention during the coming few years if the vocational rehabilitation program is to make any progress in increasing and improving upon services to the cardiac patient."

Excerpts from comments by Morris C. Hansen, C.R.C.

INTRODUCTION

Cardiovascular disease has often been referred to as the 20th Century epidemic. It has earned this reputation because of the staggering statistics on mortality attributed to this disease in the United States. According to the latest figures available, cardiovascular disease accounts for 52% of all deaths in the United States.

Regarding morbidity, it is estimated that approximately five million Americans have a history of heart attack and/or angina pectoris. Rheumatic fever afflicts 1,700,000 adults and 100,000 children. We are currently adding to those totals in large volume each year. Over 1,000,000 Americans have heart attacks each year and about 25,000 babies are born each year with heart defects.

In economic terms, it takes another vast toll. Heart and blood vessel diseases cost the American economy more than $40 billion per year in wages, lost productivity and expenses for medical care.

Atherosclerosis is recognized as the major underlying medical problem contributing to the morbidity and mortality figures cited above. One of the major medical sequelae of artherosclerosis is myocardial infarction. The disease process takes many years to develop, often without symptoms, although angina pectoris may be an earlier indication that the disease process has reached an advanced stage. After age 35 (in our population) a major increase in the number of deaths and disabilities can be attributed to cardiovascular disease. At this time of life, employment is not a new experience. Most career paths are established, although for various reasons, some individuals may not be employed at the time of infarction. Progression of the vascular problem is slow, however, myocardial infarction strikes swiftly. Approximately 20 to 25% of the people that experience myocardial infarction die before they get into the medical treatment delivery system. This has prompted many communities to initiate basic and advanced cardiac life support systems to bring prompt advanced medical treatment to the victims within minutes. Other programs are aimed at the general public to make them aware of the early warning signals of heart attack so that they can be recognized and treated early via the emergency cardiac care system. The key elements in such a system are specially trained personnel with proper equipment and drugs; a well planned procedure including a good communications system; and prompt action. An enlightened public trained in administration of cardiopulmonary resuscitation (CPR) can be of great benefit in this effort.

The diagnosis of myocardial infarction is usually fairly easy to make by physicians, although there are exceptional circumstances where the evidence is not clear cut. Electrocardiograms and blood serum enzymes ordinarily provide the necessary information, coupled with a report of the patient's symptoms.

Medical treatment for myocardial infarction, that was just a few years ago considered routine, has changed drastically. The advent of the coronary care unit with its specialized equipment, drugs and trained personnel has enabled us to deal more effectively and efficiently in treating myocardial infarction. The capability in these units to anticipate heart dysrhythmias that could result in further functional impairment, or even death, make it possible to give treatment before a crisis occurs. It is imperative that the heart muscle have as little strain as possible during the first couple of days post infarction while performing its work of supplying blood to the rest of the body. Energy level requirements have been carefully calibrated for all physical activities required during the time so that the work load of the heart can be kept at a safe level. Design of these units have put all necessary treatment modalities within easy reach and optimized patient physical recovery potential. Psychologically, we may have need for further refinement. Commonly, denial is the initial psychological problem with myocardial infarction. The patient experiencing a myocardial infarction would rather opt for a case of indigestion or muscle strain or most any other minor physical trauma. Delay in treatment, caused by denying a heart attack, results in many deaths before reaching the hospital. Denial may continue even through recover, but is not a deterrent to recovery in the later stages. Anxiety and depression are more than likely to emerge during the coronary care unit stage. Anxiety may even increase when the patient is moved to a step-down unit or general care area of the hospital. Patient education programs should be initiated in the coronary care unit. Some learning obviously does take place there, if it hasn't already taken place in the emergency room. What happened to me? Will I get better? Can I go back to work?(etc.) The length of stay in the hospital will depend on the size and location of the infarcted area, complications, and perhaps patient attitude. Increased physical activity during hospitalization helps prepare the individual for return to his home and also improves his attitude towards recovery. Less and less hospitalization time is generally being required the more we understand the individual patient's condition. Low level physical activity testing may be performed before the patient leaves the hospital. Patient-family education is particularly important during this stage. Risk factors, the identifiable conditions that place an individual at higher risk of heart attack, must be understood and a plan evolved to reduce those risk factors that can be altered. High blood pressure, smoking, high serum cholesterol levels, and diabetes are the major factors to be considered, although there are secondary factors that may need to be taken into account.

Once the patient has returned home, his activity will be increased gradually while healing of the heart muscle takes place. His physician will determine when the patient is ready for exercise tolerance testing. Test results should indicate a safe activity level for the patient and may result in an exercise prescription to maintain or improve cardiovascular fitness. By this time, the patient should be ready for re-entry to normal activity levels, including employment.

Understanding the elements of what was discussed above is essential to understanding what may transpire in social interaction and employment areas for the post-myocardial infarction patient.

We have not gone into detail on other cardiovascular conditions. Many congenital malformations that previously resulted in early death are now readily correctable. Heart valve damage (a major sequalae of rheumatic heart disease) may be surgically corrected or a valve replaced with minimum risk due to improved techniques. Better prosthetic devices for valve replacement are now available and these new valves do not impose the limitations or health hazards of previous models. Coronary bypass graft surgery is now widely practiced throughout the country. Hospital stay after coronary bypass surgery is often now less than 10 days. The latest figures indicate over 100,000 open heart operations are done each year in the United States. Additionally, more than 225,000 artificial pacemakers are functioning in living Americans now.

EMPLOYMENT BARRIERS

There is the story of the tree that fell in the forest and the resulting debate about whether it was necessary for someone to be present to hear the sound for a noise to have occurred as a result of the tree falling, or if the absence of anyone in the forest when the tree fell meant that there was no sound. We can similarly discuss the visible versus non-visible aspects of cardiac illness. Can there be a barrier if cardiac illness cannot be seen? How does one become cognizant of cardiac illness in employment? Sudden death, even though it may be reversible, is obvious. A myocardial infarction that occurs on or off the job requiring hospitalization with a medical diagnosis usually becomes known by fellow employees as well as the employer. Attacks of angina pectoris that interfere with the performance of the job may be so obvious as to be seen and recognized for what they are. Initial employment physical examinations may reveal previous infarctions, scars from heart surgery or an increased risk for future cardiac illness. Job application forms that specifically ask for health information or references from former employers or associates may account for such information being known. Knowing a physical impairment exists may or may not interfere with employability. It is how this information is used that is critical to the individual involved.

There are some general myths that persist in the job marketplace regarding handicapped workers. Some of these apply when the cardiac impaired individual is being considered for employment:

1. Insurance rates will go up.
2. Job safety will be jeopardized.
3. Job performance standards will be lowered.
4. Absenteeism will increase.

Studies have shown that health and accident insurance and workmen's compensation costs do not rise when handicapped workers are employed. These workers do not present any additional safety hazards to themselves or other workers when properly placed. They can meet production schedules, quotas, quality standards equally as well as other workers. There is no special

consideration needed for extra time off to accommodate health problems resulting from cardiac illness.

Financial incentives do exist that may encourage an individual with cardiac illness to cease work. Pension plans, workmen's compensation, social security disability benefits may have a new allure after illness depending on the person's attitude toward work or health. The employer may even encourage the employee with cardiac illness to retire early because of previous dissatisfaction with the employee's work or a perception, right or wrong, of future problems that he may not want to face with this individual. Other workers' attitudes toward cardiac illness can be detrimental to the work setting if the other workers constantly attempt to discourage the cardiac worker from doing certain aspects of his job that they consider a threat to his health. On the other hand, the employee with cardiac illness could be put in jeopardy by following orders to do some work that is beyond his physical limitations even by some well-meaning person unaware of his illness and his limitations.

A disabling condition due to cardiac illness of such magnitude that a change in job is required might evoke resistance from the employer because of disruptions to the rest of the work force or simply the extra costs involved. The employee's seniority may not be of long enough duration to displace other workers on a job that could be done by a worker with cardiac illness. The labor union position regarding seniority may be a barrier to this individual's employment.

There are four basic methods for employment of the handicapped worker:

1. Matching the worker's capability with the demands of the job.
2. Changing the worker to meet the demands of the job.
3. Changing the demands of the job to meet the capability of the worker.
4. Changing both the job and the worker to effectuate a match.

The majority of workers with cardiac illness can go back to the same job once they have been rehabilitated. The match that was initially made in employment prior to illness is simply reinstated. Cardiac rehabilitation units have fostered changes in the worker. Exercise tolerance tests from these units give safe workloads, within which the worker can function. Resulting exercise prescriptions and exercise programs improve the individual's fitness and risk factor modification programs combine to increase his capacity for surviving future attacks. Job modification is of much greater importance with other disabled groups although temperature extremes and activities requiring sudden bursts of energy, or isometrics may have to be modified for this group.

The Rehabilitation Act of 1973 has provided a challenge to industry to modify their hiring and placement practices that is without precedent in our history. It defines cardiac illness as a "severe disability" and encourages vocational rehabilitation agencies to give priority for working with severely handicapped individuals. The record shows, however, that the percent of cardiacs receiving services from state vocational rehabilitation programs has

declined over the years. Effective enforcement of the Rehabilitation Act could result in much greater employment opportunities for cardiacs. Social Security statistics show that the largest group receiving Social Security disability benefits is the cardiac group. These same statistics show that cardiacs are one of the largest groups denied disability benefits. Thus, cardiacs are often proclaimed not capable of work by one segment of society and not ill enough to receive disability compensation by another segment of the same society.

SOCIAL BARRIERS

Persons afflicted with cardiac illness, their families and associates, need more information about their illness, its treatment, limitations it imposes and its prognosis. The diagnostic and treatment modalities are not well understood by patients and the general public. Often little interest is given to this information until the time the cardiac illness strikes the individual, a family member or close associate. A scramble for the facts at this juncture is often confusing. Emotional responses to this very critical "life-death balance" of myocardial infarction further confuses the issue. The physician is often under the impression that his explanation of the illness to the patient or his family was sufficient to make them aware of all that was needed to be known. Unfamiliar medical terms, emotional state at the time of explanation, as well as any communication difficulty on the part of the physician or other medical person giving the explanation interferes with its effectiveness.

Little is known by the general public about exercise tolerance tests, angiography, heart valve surgery, coronary bypass graft surgery, other types of open heart surgery, pacemakers, defibrillation, electrocardiograms, blood pressure measurements, cardiac drugs or other diagnostic or treatment modalities used for cardiac illness.

The patient returning home from the hospital is a different individual in many respects than the one who entered the hospital. A portion of heart muscle has died, physical capacity, markedly reduced initially, has begun to improve. Stresses of everyday life previously tolerated without much thought may now be amplified. Hidden fears may emerge. Challenges to masculinity (Can I fulfill my role as a sexual partner?), guilt (Was it something I did that caused the illness?), all may be part of the scene when the patient returns home. The emotional stress may be within the patient, the family or friends.

The home surroundings bring expectations that previous activities engaged in routinely before illness can be picked up without difficulty and anything less is a loss of self-image. Friends drop by to wish the patient well and may complicate his recovery by tiring him out with extended visits. Children may be told that the usual routine must be changed (Keep quiet. Don't argue with Daddy, etc.). Things left dangling regarding work tend to sneak back into the picture. The myocardial infarction was not an anticipated event, and as with all emergencies, left some things unfinished. The employer may be looking for solutions to business problems that only that individual can provide, or may be making plans to function without him. Either situation can creat anxiety. Loss of income and mounting medical costs can create tremendous economic problems for the individual and the family.

Until the time when exercise tolerance testing can be performed, the patient usually operates on his own with general instructions from his physician about what to do during this interval. Having the results of this test generally means that decisions about employment may be made. We now know what energy level activity can be tolerated safely. The safety limitations have to be measured against the demands of the job. Often this is the weak point since jobs are not classified according to the energy expenditures necessary to complete them. A gradual return to full employment may be indicated, but no firm rules exist to gauge levels here either. Conflict may exist between the family physician who urges return to employment and the industrial physician who feels return is not indicated. Misunderstandings about cardiac illness may exist within the personnel staff or foreman or other supervisor that may prevent acceptance back to employment without good reason. Modifications of jobs to accommodate the employee in terms of heavy lifting, temperature control, or features that involve the safety of other workers, require special skills not usually found in the field of Rehabilitation.

Insurance is a problem for individuals with atherosclerotic disease, congenital heart defects, heart surgery patients, and other heart problems. It is often difficult if not impossible to obtain health or life insurance once the disease is recognized to exist. Even people with drug controlled hypertension pay higher rates for insurance. Health insurance companies are often reluctant to pay for cardiac rehabilitation services. With discharge from the hospital occurring as early as one week after infarction, we may have to restructure the entire cardiac rehabilitation process. Insurance companies should readjust their rate and payment schedules to meet the new needs.

Agencies dealing with rehabilitation should look at the special needs of the cardiac client. The Federal-State Vocational Rehabilitation figures show a decline in the number of patients served since 1967. The rate, percentage-wise, has been reduced from 3.5% to about 2%. There is a reluctance to initiate services early despite the fact that early intervention is one of the key components of good recovery from this illness. Vocational counselors need to be redirected from their traditional thinking about waiting to rehabilitate a client until he has had at least several months of medical treatment. Counseling should begin as soon after release from the coronary care unit as possible.

There are certain other social impediments to the assimilation of the cardiac back into society. Many state driver's license application forms make inquiry about heart attack, hypertension, etc., as a screening device. Patients use of nitroglycerine publicly causes consternation with associates ("What will I do if he has another heart attack?") A healthy looking man may be asked to perform a heavy labor task or participate in a sporting event beyond his capability. He may appear asocial in his non-participation. Dietary restrictions caused because of this illness are often hard to follow, particularly if one has to travel extensively in his work.

Much research is being done and needs to continue in many areas. For example, cardiac drug therapy has improved in this field during the last few years and anti-hypertensive agents and anti-arrhythmic drugs are but two examples. Our primary goal in research should be for prevention of the disease. Early

ambulation and discharge from the hospital has begun, but needs to be studied further. As we reduce the time spent in-hospital, we need to develop new methods for delivery of patient-family education. More consideration needs to be given for a structure of the time interval between discharge from the hospital and return to employment. We need to have jobs studied and classified in reference to their "energy requirements" so that we can make a better matching of the worker and the job. The effects of physical conditioning on cardiovascular fitness also needs to be studied. The coping mechanisms that result in one person becoming a "cardiac cripple", while another with the same amount of physical damage readily assimilates back into society, needs to be studied.

Legislation such as that provided in the Rehabilitation Act of 1973, can be of great benefit to cardiacs. Sections 501, 503 and 504, properly enforced, can help alleviate many of the areas of job discrimination that now exist. Perhaps some further look at those cardiacs turned down for Social Security disability benefits is necessary. Maybe a requirement for some special rehabilitation services for this group would pay dividends. In addition, Workmen's Compensation and Second Injury laws should be standardized throughout the country.

We can certainly, in our lifetime, make a large impact on the premature death and disabilities that occur from cardiovascular disease and some progress can already be seen. Let's hope that soon we can go back upstream in the disease process so that we can begin the rehabilitation process earlier, concentrating our efforts on treatment to prevent myocardial infarction instead of treating it after its damage has been done to the heart muscle.

NOTE: The REFERENCES for this chapter are found at the end of Chapter 6.

CHAPTER 6

CARDIAC ILLNESS: ACTION FOR IMPROVING SOCIALIZATION AND FAMILY SUPPORT, AND REDUCING STIGMA AND NEGATIVE ATTITUDES

Author: Robert M. Levenson, M. D.

"I would indicate that the author has very ably raised several significant problems which will require our attention if, indeed, rehabilitation services are to be expanded to meet projected needs in the 1980's.

"The identified need for increased public and employer education is indeed a critical one. Greater awareness and understanding is mandatory if service and opportunity are to be expanded to meet the needs of cardiac patients.

"An issue of significant concern to the vocational rehabilitation program is the medical profession's lack of information regarding the existence and purpose of the vocational rehabilitation program and the need for vocational guidance services as a component of the cardiac rehabilitation process."

Excerpts from comments by Morris C. Hansen, C.R.C.

"This paper does point out a need for more emphasis in state vocational rehabilitation agencies on understanding the many ramifications related to rehabilitating a person with a cardiac condition. Some solutions are offered; however, they do not appear to be sufficiently aggressive to make an impact on state vocational rehabilitation agencies in a short period of time. Statements regarding the education of physicians and medical students do not tend to show an aggressiveness either toward utilizing 'teams' presenting more positive expectations to patients with cardiac conditions, and modifying practicing and new physicians' behaviors relating to contemporary cardiac rehabilitation processes."

Excerpts from comments by Hank E. Graden, C.R.C.

INTRODUCTION

In the field of heart disease many dramatic changes have taken place over a relatively short time. This changing scene requires a careful assessment of current needs, current problems and attitudes regarding heart disease.

The heart problem is still that of the atherosclerotic process. Rheumatic fever has dramatically decreased in frequency and while congenital heart disease has not decreased, it is in most instances (in part, if not entirely) correctable by surgery.

With the advances in both medical and surgical therapy, and perhaps related to this, the mortality for coronary heart disease has diminished approximately 12% since 1970. Better control of the various kinds of cardiac rhythm disturbances and broader control of hypertension are among the principal contributions to this decrease.

Coincident with the development of the coronary care units in 1965, there has been a marked reduction in the length of hospital stay for the myocardial infarction patient. This has served to decrease the level of physical disability and prolonged inactivity, as well as diminishing the tendency toward invalidism. Obviously, this also has reduced hospital costs. Early ambulation and activity programs are now available in most hospitals. These allow individuals with heart problems to pursue a course of graded activity intended to get them back to normal levels of functioning. In addition, many community conditioning programs are available which enable individuals, both cardiac and non-cardiac, to maximize their physical abilities.

The consequences of these activities and programs has been to decrease the image of cardiac disability. Seeing an individual known to have had a "heart attack" returning to work within six or eight weeks, or seeing such an individual begin to participate in activity programs or carrying out his own work has been a most valuable educational activity for the community. Probably no other program has served to demonstrate so clearly the ability of most individuals with heart problems to resume their normal mode of living quickly and effectively.

Nonetheless, some problems continue. For example, at least 20% of individuals in the "working age-group" (30-60) do not resume regular work or even moderate activity after undergoing coronary bypass surgery. They may restrict their activities because of other heart problems or may simply decide that they no longer care to work.

Sudden death continues to be the first sign of a cardiac problem in many individuals. Clearly there is a need for earlier means of detection of heart disease, including the suspicion that sudden death may occur. Since there is a tendency for cardiac arrest to recur, a need also exists for better means of treatment.

At the present time, relatively little concern has been paid to the social and vocational problems and potentials of the individual who is being considered for coronary bypass surgery. The major concern has been the anatomy of the coronary arteries. This problem is being addressed and it's likely that much more attention should be given to this area. Similar problems still exist for many patients after a myocardial infarction.

There remains a clear need for early counseling regarding activity and work for the individual who has suffered a cardiac problem or who is undergoing cardiac surgery. It is evident based on many experiences, that vocational counseling be instituted as quickly as possible in the course of the illness or in surgery, even before the operation is performed. The opportunity for a successful social and vocational outcome can be dramatically improved with early intervention.

ACTIONS FOR IMPROVING SOCIALIZATION

Social acceptance of cardiac problems by the community can be improved still further if programs are mounted which emphasize the "positive features" of the illness. For example, the ability of the individual to resume normal activity, including work, following a myocardial infarction or coronary bypass surgery, needs to be emphasized. For the community, as well as the individual and his family, the patient's functional ability, not disability, needs to be stressed.

Such broader positive achievements as the reduction of the frequency of myocardial infarction and the effective control of hypertension deserve to be reiterated as often as possible.

Information of this kind can and should be disseminated widely at both national and local levels. The mass media (television, radio and the press) serve as an important means of providing cardiac information to many groups. Such information and various programs are available either through the Heart Association, nationally or locally, as well as the National Heart and Lung Institute or other government health and rehabilitation agencies. Speakers, programs, handouts, films, etc. can be used with great effect, and, in certain areas, local or statewide programs have demonstrated the effectiveness of this approach in providing information to the public.

In addition, consideration needs to be given to programs of health education that might be conducted in the school systems. With the problems of crowded curricula and inadequate education in health matters, such programs do not exist at the present time. However, if suitable instruction and teaching aids were provided within the system, the students could be given an opportunity to gain a base of knowledge in health matters to which further information could be added at a later time.

These kinds of programs have important implications for many segments of the community. A voluntary health agency, such as the Heart Association, considers health education as a part of their goal. They could easily be called upon to provide their expertise in areas that would be of value to the public. In addition, large industries have become more receptive to health education programs. They now recognize that maintaining their employees in good health can actually serve to reduce many of their health and financial obligations. Thus, conditioning programs, exercise testing programs and lectures on health matters are now readily available in many industries and are frequently conducted on company time. In addition, recreational facilities, such as tennis or jogging facilities, may be made available by the industries. If it could be convincingly demonstrated that these programs do, in fact, function as promised, they should be widely replicated throughout the country.

Health Departments, both local and state, should participate in various health activities. They are charged with the maintenance of health, and for this reason, are usually willing to become involved where it is feasible. Frequently they have resources available that could allow effective and relatively inexpensive programming.

There is a model that can serve as a guide for the development of new national programs. It is known as the National Hypertension Program and has been underway for several years. This represents a cooperative effort by the medical community, government, voluntary health agencies, community agencies and pharmaceutical companies. All are working together to make the public aware of hypertension, and also to develop new knowledge and encourage research and control of this disorder. This has been accomplished by arranging meetings of various groups, by supporting programs of hypertension detection, supporting and encouraging research in the area of hypertension and by participation in meetings of medical and public groups.

All of these activities have served to make the entire country acutely aware of blood pressure problems and the effectiveness of treatment. As indicated earlier, a part of the decrease in heart disease mortality may be related directly to the Hypertension Program. It is obvious that another disorder could be substituted for hypertension and, if the appropriate resources were involved, the disorder could be equally well brought to the attention of the public and with hopefully equal effectiveness.

The actions for improving family support are essentially those aimed at improving community knowledge of heart disease. A positive attitude by the medical team, a proper explanation of the disorder, its processes that caused it to develop, and a program to forestall further cardiac problems require much emphasis if it is to be understood by the individual and his family. However, if a background of community education does exist, the additional features may be described simply and will be readily understood.

For the individuals who have problems in the social, vocational or emotional areas, in addition to heart problems, it is important that early recognition and appropriate referral be instituted. It is reported, in general, that emotional problems of the cardiac individual are often resolved by the resumption of normal activities. However, the vocational concerns may continue and, in fact, be realistic for many individuals. Thus, early counseling regarding vocational choices and job changes is important. Unfortunately, as mentioned earlier, there continues to be a lack of recognition by the medical community of the potential of vocational counseling in dealing with the cardiac patient. This has occurred for a number of reasons.

1. The medical profession, in general, apparently is unaware of the existence of the Division of Vocational Rehabilitation (D.V.R.).

2. There have been unfortunate experiences by those who have dealt with D.V.R. in recent years. This has come to pass, in good measure, because the agencies were mandated to spend much of their resources and time in dealing with specific hard core unemployables. This has generally tended to exclude the possibility of working with cardiac individuals.

   In addition, many of the counselors are uncomfortable in dealing with cardiac patients. There continues to be a need for the education of counselors to develop a good background knowledge that will enable them to deal more effectively with the cardiac client.

At the present time, new legislation is probably not needed. Emphasis on the regulations of the Vocational Rehabilitation Act of 1973 should take care of many of the problems of the employer refusing to return the cardiac patient to work. However, a concerted effort is needed to make certain that this mandate is being utilized.

Studies on the effectiveness of various programs in returning individuals to normal activity and innovations which will allow for early intervention by vocational counselors or preoperative intervention by counselors and social workers on bypass patients clearly seem indicated, and might be done in a number of centers throughout the country. The cost of such programs would be relatively small and they could provide crucial information necessary for projects of this nature.

ACTION FOR REDUCING STIGMA AND NEGATIVE ATTITUDES

As mentioned earlier, the basic approach of describing the individual's functional capacity and not his disability, and the attitude by the medical team of their expectations of his resuming normal activity are critical, especially in the early phases of treatment.

Early recognition of the anticipated and "normal" depression that occurs and reassurance that it will disappear without therapy other than an activity program, is very important, both to the individual and to his family.

In the past, work evaluation units served to be a focus of describing positive responses of individuals. While the work evaluation type of activity is probably no longer needed, there is a continuing need for a resource to which individuals could be referred for in-depth evaluation, counseling, social service evaluations and vocational evaluations in a short time, and hopefully, at a low cost. Such a program should be conducted by individuals who are able to work together, who respect the other disciplines and who could discuss, on a one-to-one basis, the findings and recommendations.

At the present time, new legislation does not seem to be necessary. Most major employers recognize the ability and safety of the cardiac individual at work but there are still some jobs which are precluded for cardiacs and this will always be. Specifically, such work as lumbering, flying of aircraft, will probably never be available to most individuals with a cardiac condition.

In summary, the changes of the last twenty years have generally been highly favorable toward the recognition that the individual with a cardiac problem can usually be expected to regain much, if not all, of his function. The positive attitude and the emphasis on functional capacity or ability, and the shortening of time in the hospital, plus the early ambulation programs, have substantially reduced both hospital inactivity and total time away from work. There continues to be a need for earlier intervention however, by other than the medical personnel, if optimum service is to be offered. The implementation of early intervention activities by other professionals on a pilot scale clearly seems in order.

REFERENCES

1. DHEW Publication No. (NIH) 75-750, Needs and Opportunities for Rehabilitating the Coronary Heart Disease Patient. December 1974, Report of the Task Force on Cardiovascular Rehabilitation of the National Heart and Lung Institute.

2. DHEW Publication No. (SSA) 75-11911, Worker Disability Allowances, Social Security Disability Applicant Statistics, 1973; U.S.Department of Health, Education, and Welfare, Social Security Administration, Office of Research and Statistics.

3. Heart Facts, Copyright 1977, American Heart Association.

4. Glenda K. Barnes, R.N.; Marjorie J. Ray; Albert Oberman, M.D.; Nicholas T. Kouchoukos, M.D., Changes in Working Status of Patients Following Coronary Bypass Surgery, JAMA, September 19, 1977-Vol. 238, No. 12.

5. Public Policy Reference Paper, American Heart Association, 1978.

6. Report of the Committee on Stress, Strain and Heart Disease, Reprinted from Circulation, Vol. 55, No. 5, May 1977, American Heart Association.

7. Report of the Committee on the Effect of Strain and Trauma on the Heart and Great Vessels, Circulation 26:612, 1962, American Heart Association.

8. Minority Report of the Committee on the Effect of Strain and Trauma on the Heart and Great Vessels (J. C. Paterson), Circulation 28:266, 1963, American Heart Association.

9. Proceedings of the National Invitational Conference on Stress, Strain and Heart Disease, October 10-12, 1968, American Heart Association.

10. A. B. Chandler; I. Chapman; L. R. Erhardt; W. C. Roberts; C. J. Schwartz; D. Sinapius; D. M. Spain; Sherry S. Ness, P.M.; T. L. Simon; Coronary Thrombosis in Myocardial Infarction; report of a workshop on the role of coronary thrombosis in the pathogenesis of acute myocardial infarction. Am. J. Cardiol. 34:823-833, 1974.

11. M. Friedman; R. H. Rosenman; Type "A" Behavior and Your Heart, Alfred A. Knopf, Inc., New York City, 1974

12. AHA, Committee on Exercise, Exercise Testing and Training of Apparently Healthy Individuals: A Handbook for Physicians (70-008A), American Heart Association, 1972.

13. AHA, Committee on Exercise, Exercise Testing and Training of Individuals with Heart Disease or at High Risk for Its Development: A Handbook for Physicians (70-008B), American Heart Association. 1975.

14. S. M. Fox; J. P. Naughton; P. A. Gorman; Physical Activity and Cardiovascular Health. Modern Concepts of Cardiovascular Disease 41:17-30, 1972.

15. R. S. Paffenbarger, Jr.; W. E. Hale; Work Activity and Coronary Heart Mortality, New England Journal of Medicine 292:545, 1975.

16. Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC). Supplement to JAMA, February 18, 1974.

17. Characteristics of Clients Rehabilitated in Fiscal Years 1967-1971; Federal State Vocational Rehabilitation Programs; U.S. Department of Health, Education, and Welfare, Social and Rehabilitation Service, Rehabilitation Services Administration, (SRS) 73-25055.

18. J. Frederick McNeer, M.D., et al, Hospital Discharge One Week After Acute Myocardial Infarction; The New England Journal of Medicine, Vol. 298, Number 5, February 2, 1978.

19. Gopal C. Pati, Countdown On Hiring the Handicapped, Personnel Journal, March 1978.

20. Insurability and Employability of Young Cardiacs, Special Report, Circulation, Vol. 56, No. 2, August 1977, American Heart Association.

21. Susan Bowar-Ferres, R.N., M.S. Returning to Work - Another Stage of Recovery and Growth for the MI Patient; Occupational Health Nursing, November 1975.

22. Early Discharge After Heart Attacks and the Efficient Use of Hospitals, The New England Journal of Medicine, February 2, 1978, Vol. 298, No. 5.

23. Ned H. Cassem, M.D. and Thomas P. Hackett, M.D., Patient Psychology, American Heart Association, 1975.

24. Thomas F. Garrity, Vocational Adjustment After First Myocardial Infarction: Comparative Assessment of Several Variables Suggested in the Literature, Soc. Sci. & Med. 1973, Vol. 7, pp. 705-717, Pergamon Press. Printed in Great Britian.

25. Kushnir, Fox, Tomlinson, Portal and Aber, The Influence of Psychological Factors and An Early Hospital Follow-up on Return to Work After First Myocardial Infarction, Scandinavian Journal of Rehabilitation Medicine 7:158, 162, 1975.

26. Shapiro, Weinblatt, and Frank, Return to Work After First Myocardial Infarction, Archives of Environmental Health - Vol. 24, January 1972.

27. DHEW, Guidelines for the Development of Cardiac Rehabilitation Programs: February 1976, Office of Human Development, Rehabilitation Services Administration, Washington, D.C.

28. Hanman, Bert, Physical Capacities and Job Placement; Nordiek Rologrough, Stockholm, 1951.

SUMMARY OF IMPLICATIONS FOR CARDIAC REHABILITATION

SERVICE DELIVERY NEEDS

Early referral (or intervention) to Vocational Rehabilitation cannot be stressed enough. Case finding should be achieved prior to the client's leaving a coronary care unit.

A "team structure" should be developed in each hospital in which the Rehabilitation Counselor could be an integral part. This would also place the Counselor in an ideal position to receive referrals early in the treatment process.

In order to enhance the job placement process, more extensive use of current legislation is needed, e.g., Sections 503 and 504 of the Rehabilitation Act of 1973. Precedent-setting cases should be gathered for use as evidence.

In Rehabilitation Counselor education and continuing education, the role of "counseling" and a deeper understanding of psychosocial implications of those with cardiac disabilities needs a new emphasis.

The Rehabilitation Counselor can and should provide the following services to the cardiac client: job analysis, job placement assistances and post-employment services, which are all too often lacking in the rehabilitation plan. Obviously, the function of 'counseling' should be taking place throughout all of the above tasks.

There are "cardiac assessment resources" available for use by Rehabilitation Counselors and should be utilized more than they are at present.

Increased use of sheltered work facilities were recommended as an excellent modality to improve "work hardening" skills to develop greater work tolerance.

Early case finding for young persons is needed to prepare them for Vocational Rehabilitation programs. For those with congenital and rheumatic heart problems, career counseling should begin as early as feasible.

Greater attention needs to be focused on the creation of self-help groups. In this instance, peer counseling with Rehabilitation Counselors as resource persons can be of real value in the overall adjustment process. The positive value of peers that "have made it" can be useful models for encouragement and support.

Vocational Rehabilitation Counselors should become familiar with the array of support systems in their community in order to encourage and refer, e.g., know when and where to send a client for family or social service or patient and family education programs. Only an aware counselor will be able to make such a referral.

The need for more advocacy activities in cardiac rehabilitation still exists and should be well-planned in order that impact be made in this area. In addition, community education regarding the abilities of the cardiac client and the return to activities of daily living need to be known and understood. The employer, as well as the general public, must have more information in this area.

PROGRAM AND POLICY DEVELOPMENT NEEDS

The role of the Vocational Rehabilitation Counselor in cardiac rehabilitation must be clearly defined, especially the emphasis on job analysis, job placement, vocational-medical intervention and supportive counseling which is all too often neglected.

The number of persons entering the Social Security Disability system can be reduced by improving screening methods and also by developing more aggressive cardiac rehabilitation programs.

State Vocational Rehabilitation (VR) Programs need clarification via Federal policy as to questions of eligibility, e.g., are cardiac clients severely handicapped; how soon after onset will Vocational Rehabilitation be able to determine eligibility; and is the person returning to work, but vocationally handicapped, eligible for VR services? Questions of this nature need immediate attention and clarification.

Federal policy should be developed that includes myocardial infarction and surgery to qualify one as severely handicapped.

Increased flexibility of third party payments is needed for rehabilitation services, especially for major hospital/medical insurers.

Methods must be developed to make the VR Counselor a more visible service provider to the cardiac client.

Improved working relationships should be fostered between VR and State Heart Associations. In the long run, the client is the beneficiary of positive relations of this type.

Attitude change can be brought about by VR action through the VR State Medical Administrator, field medical consultants and medical societies. Just as VR Counselors need improved skills and awareness in cardiac rehabilitation, so do the medical specialties and general practitioners in the area of what can be done for the cardiac in terms of total rehabilitation.

The cardiac consumer must also join the move for greater services in his/her behalf. The public needs to become aware of the benefits of cardiac rehabilitation.

Community and patient education programs could help reduce the misinformation and improve public attitudes toward those with cardiac disabilities.

Cardiac assessment resources are in need of further development in order to assist the VR Counselor to better understand the work potential of cardiac clients.

Follow-up studies are recommended to determine what happens to those denied Social Security Disability benefits, e.g., do they return to work, go on public assistance, etc.?

Future versions of the Dictionary of Occupational Titles (D.O.T.) should include "energy expenditures" related to cardiac abilities.

Planned programs for advocacy activities in cardiac rehabilitation are encouraged and this would tie in closely with the approaches for educating the VR Counselor, the medical community and the public as described above.

RESEARCH NEEDS

More research needs to be undertaken in the area of physical demands of work as related to cardiac abilities.

Research involving the follow-up of cardiac denials of Social Security Disability benefits should be initiated.

Self-help groups: It was recommended that self-help groups and peer counseling be evaluated for their worth in the rehabilitation of cardiac clients.

Studies are also necessary in understanding the problems of insurance coverage and driver's license restrictions, since there are gross inequities found in these areas from State to State.

LEGISLATIVE NEEDS

Laws pertaining to Workmen's Compensation and Social Security Disability are in need of serious modification in order that rehabilitation incentives are built in to future statutes. Currently, the disencentives to rehabilitation outweigh the real benefits. This would also mean a reduction of those entering the Social Security Disability system.

The development of financial subsidies, i.e., rehabilitation incentives should be explored until a client is successfully back to work.

Federal mandates need to be encouraged in dealing with insurance problems and those of driver's licensing. In both instances, only national initiatives will make a difference, otherwise State-to-State differences and inequities will remain.

CHAPTER 7

COMMONALITIES OF THE INVISIBLE HANDICAPS

> "An issue common to 'invisible' handicaps is the assumption that one cannot see the problem. It follows that if something is not noticeable, that there is little incentive to deal with it; in fact, people do not deal with that of which they are unaware. It occurs to me that a general mission regarding 'invisible' handicaps is, therefore, to make them visible or noticeable because then important elements in society that present barriers to personal and vocational adjustment will be forced to think about and deal with such problems. But uncertainty lies in predicting just what will be thought and/or what will be the manner of dealing with these disabilities by the community of man.
>
> An additional rather esoteric issue involves just what the 1980's have in store for all of us. Is it not possible that further technological advances will result in fewer available jobs, thus straining the potential for success of the effort to impact the attitudes of persons with disabilities and the community at large? Is it not possible that international economic and social problems might result in increased dependency upon government for social services, thus reducing the incentive for independent living? Will there be financial support for rehabilitation efforts in the 1980's? These questions relate to program development and legislation, but also to those factors over which there is little control; nevertheless, consideration of the matrix within which rehabilitation will exist in the 1980's might be useful."
>
> Excerpts from comments by G. Fred Cromes, Jr., Ph.D.

After discussing the Action Papers from a categorical standpoint, it became quite clear that there were a number of issues, questions and solutions that cut across specific disabilities. These issues, common to the invisible handicaps, were discussed at the Seminar and are abstracted in this segment of the report.

One area, which is of utmost importance in understanding the rehabilitant, is the effect of their disability on the disruption of life style, i.e. the client's family, significant others and the dynamics that may occur as a result of the disability, whether it be a heart condition, cancer, epilepsy or any other disorder which is invisible.

In any of the above, there is a good chance that the medical aspects will often be an ongoing process. Our focus then, from the standpoint of rehabilitation, will need to become more sensitive to the psychosocial issues

involved in the client's adjusting to a catastrophic situation (recognizing that catastrophe is a highly individualized perception). The discovery of cancer, heart disease or epilepsy may signal a wide array of feelings, including fear, anxiety or doom to any given individual. These very same kinds of feelings may also be evidenced by that person's family, friends and employer.

It is obvious that if the Rehabilitation Counselor is to provide optimum services to the client that a better understanding of the psychosocial aspects of those with the invisible handicaps is imperative. In addition, there will be a greater reason to provide counseling around these psychological factors, including the ability to make sound referrals for additional psychiatric/ psychological services, when warranted.

To accomplish the above, the educational process (regarding these disabilities) will need to be expanded to include rehabilitation counselors, social workers, psychologists, medical personnel and others expected to work with these persons toward their total rehabilitation. The educational process should stress the dispelling of myths and stereotypes and the reduction of negative attitudes on the part of the health care and rehabilitation providers.

Another area which must be addressed if we are to make any significant movement in rehabilitation is the need for better "teamwork" with the various disciplines involved in fulfilling prescribed services. While this approach is not a novel one, its merits must be re-emphasized where it already exists and developed where it does not. After all, we have only the patients' rehabilitation at stake.

Also requiring our attention is the emphasis on the value, role and function of peer groups. This is especially significant with the increased thrust of consumer involvement. There are many persons who have a hidden disability and yet continue to function, create, work, etc. Others, still learning to adapt to their disability, may benefit greatly in knowing that a person with a similar disability "made it."

From the research point-of-view, it would be valuable to understand how others have achieved rehabilitation since there are significant numbers of people with invisible disabilities that are functioning adequately in society. The question is how did <u>they</u> do it, and what in their rehabilitation process made the difference? To the researcher, the crucial question is one of finding these cases to study, since "stigma" of the feeling of "being found out" (i.e., I have a cancer, epilepsy) often makes the availability of subjects a difficult task.

The overriding commonality is the fact that there are persons with various hidden disabilities who are able to function well and in a variety of settings. Our task is to ensure that those who are functioning at a minimal level are given the best possibel resources to enhance their rehabilitation potential.

A LIST OF COMMONALITIES

Numerous commonalities among the invisible handicaps were isolated by the Fellows, along with recommended actions that could serve persons with the disabilities under study. These are shown as follows.

1. Recommendations for additional educational activities such as:

   a. Client and family education, including information about the disability and methods for coping and adjusting.

   b. Professional education for the medical profession and the rehabilitation counselors regarding psychosocial needs, evaluation procedures and coordination and utilization of community resources.

   c. Community education for employers and the public regarding the abilities of workers with hidden disabilities, information about such disabilities and related affirmative action legislation.

2. A need for effective interagency cooperation, e.g. between the medical profession with public and private support programs, with vocational rehabilitation and with disability associations and societies.

3. A need to deal with attitudes about the "invisible disabilities" including:

   a. Client attitudes and reactions to the disability or situation.

   b. Family reaction to the situation and the disabled individual.

   c. Professionals' attitudes, e.g. physicians, health care professionals and rehabilitation counselors.

   d. Public stereotypes - including employers.

4. Psychosocial and mental health problems are fairly common to those with "invisible disabilities" and may include one or more of the following:

   a. Fears and anxieties.

   b. Depression.

   c. Rejection.

   d. Loss of self-esteem.

   e. Dependency.

f. Denial.

g. Problems of social acceptance.

h. Problems in dealing with stigma.

5. Employment problems that may accompany invisible disabilities exist, such as:

   a. Lack of information by the employer, including fear or rejection.

   b. Fears of the affects of disability on work performance (by either employee or employer).

   c. Discriminatory hiring practices.

   d. Negative co-worker attitudes.

   e. Danger (real or perceived) associated with specific types of jobs.

6. A need for definition or determination of the vocational rehabilitation role in comprehensive treatment and rehabilitation process.

7. A need for greater vocational rehabilitation outreach from the medical profession, hospitals, etc., in order to provide information about available services and to solicit referrals.

8. A need for earliest possible vocational rehabilitation counselor intervention in the treatment process.

9. The rehabilitation team approach is needed to optimize patient services.

10. The rehabilitation process for each of the "invisible disabilities" begins with diagnosis. Both comprehensive medical and psychosocial evaluation is required.

11. Emphasis should be placed on functional ability rather than "disability," as it is currently found all too often.

12. Self-help/peer groups may provide assistance in the rehabilitation effort.

13. There is need for better methods of measuring rehabilitation outcomes when self-help groups are utilized.

14. There is need for minimal service standards pertaining to all areas of service delivery for those with invisible handicaps.

15. A need for training health team members on communications techniques.

16. A need to identify determinants of vocational rehabilitation success.

17. There is a significant effect upon lifestyle of patient and family, and this should be understood by the rehabilitation team.

18. Patients with "invisible disabilities" are often discriminated against by insurance companies by denial of coverage and the payment of increased insurance rates.

19. The vocational rehabilitation program often experiences difficulty in serving clients with "hidden disabilities" due to program requirements, e.g. eligibility, production quotas, etc.

20. A multi-dimensional basis for measurement of severity of disability is required to determine degree of loss and extent of remaining or transferable abilities.

21. Greater emphasis upon rehabilitation counseling is required stressing the functioning of the counselor as a counselor.

IMPLICATIONS FOR SIMILAR LEGISLATIVE ACTION FOR THE INVISIBLE HANDICAPS

EMPLOYMENT

- The Authorization for Appropriations Under the Rehabilitation Act will Need to be Increased.

  It is expected that the actions contemplated in this seminar will result in the referral of increased numbers of individuals with "hidden" disabilities to state rehabilitation agencies. In order to handle this increased caseload, more counselors and related staff and more case service funds will be needed unless this group "replaces" some other disability group. The latter is untenable.

- The Financial Disincentives to Participation in a Rehabilitation Program Should be Eliminated.

  The provisions of the Social Security Act, especially those dealing with disability and with health care for the poor, operate effectively to discourage disabled individuals from pursuing rehabilitation due to the level of benefits and range of services as well as difficulty of restoration to the roles in a timely fashion in the event of failure.

COMMUNITY PARTICIPATION

- The Rehabilitation Act Should be Amended to Provide for Services for Individuals with less than Vocational Goals.

  The discussions made clear that there are large numbers of persons with heart disease, cancer, and epilepsy whose rehabilitation needs are not primarily vocational. Most of these persons need medical and psychosocial services but may not expect to achieve full-time vocational goals. No legal base for these services currently exist.

- Any National Health Insurance Schemes Should Include Services for Those with Invisible Disabilities.

  The considerable emotional overlay of this group alone should qualify them for health insurance programs for psychosocial counseling. This issue is further complicated by the chronicity of these disorders. The need for a positive action program to keep the client functioning at a high level of activity hinges upon support when needed.

SOCIALIZATION AND FAMILY SUPPORT

- Enforcement of Existing Legislation is Needed.

  The individuals with "hidden" disabilities are often subjected to discrimination in many of the spheres of daily living, such as access, recreation or family functioning. Since there are statutes covering these areas, e.g. Sections 501, 503, 504 of the Rehabilitation Act, there needs to be a greater commitment to their enforcement.

STIGMA

- Attitudes Toward People Cannot be Legislated.

  It became obvious in the discussions that those with invisible handicaps encounter a variety of negative attitudes on the part of the general public. This, in turn, is obviously distressing to the disabled persons. The seminar focused on the need for an educational rather than legislative solution.

THIRD PARTY PAYMENTS

- Additional Sources of Funding

  There is a need for additional third-party payments for building a funding base for provision of a wide array of needed services in the rehabilitation process.

BOARD OF DIRECTORS
NATIONAL REHABILITATION ASSOCIATION
1978-1979

OFFICERS:

President	Elizabeth H. Anderson New York, New York
President-elect	Michael A. Oliverio Morgantown, West Virginia
Treasurer	Marlys Anderson Sacramento, California
Immediate Past President	Carl E. Hansen, Ed.D. Austin, Texas

BOARD OF DIRECTORS

Oswald Sykes Brooklyn, New York	Judy Spolum Denver, Colorado
Sheila M. Williams Washington, D. C.	Margie Sloan Atlanta, Georgia
James B. Adams Paducah, Kentucky	Phil Chase Fayetteville, North Carolina
Bob Horvath Lansing, Michigan	Henry Williams New York, New York
Bill Bain Lancaster, Texas	Bernadette Kuhlman Sacramento, California
Jerry Starkweather Des Moines, Iowa	Fred Board New York, New York
James Organist, Ph.D. Tucson, Arizona	Stephen Bonowski Indianapolis, Indiana
William Burnside Springfield, Virginia	Lucille Zuber Santa Fe, New Mexico
Norma Jo (Jody) King Lawton, Oklahoma	David A. Schriemer Tallahassee, Florida
Patricia Mundt Carson City, Nevada	Betty S. Hedgeman, Ph.D. New York, New York
Vernon Hawkins Washington, D. C.	Arnold B. Sax, Ed.D. Menomonie, Wisconsin
Elton A. Price Trenton, New Jersey	Michael Nelipovich Little Rock, Arkansas
Marvin Spears St. Paul, Minnesota	James R. Burress Washington, D. C.

COMMISSION ON PROFESSIONAL CONCERNS

Henry Williams, Chairperson
New York, New York

Marlene Nelson
Associate Chairperson
Salem, Wisconsin

Gladys McCauley
Cleveland, Ohio

David A. Schriemer
Tallahassee, Florida

James Organist, Ph.D.
Tucson, Arizona

Brockman Schumacher, Ph.D.
Carbondale, Illinois

Gwen Countryman
Little Rock, Arkansas

Phil Chase
Fayetteville, North Carolina

James Ramseur
Central Islip, New York

David Williams
Harrisburg, Pennsylvania

MARY E. SWITZER MEMORIAL COMMITTEE

1977-1978

Olive K. Banister, Chairperson
Betty S. Hedgeman, Ph.D., Associate Chairperson
Edward F. Rose
William M. Usdane, Ph.D.
David Roberts, Ph.D.
Elizabeth H. Anderson, (ex officio)
Carl E. Hansen, Ed.D., (ex officio)
Richard P. Oestreich, (ex officio)
Henry Williams, (ex officio)
Leonard G. Perlman, Ed.D., (ex officio)